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**Exploring nutritional therapy practitioner perspectives on
working with people affected by cancer**

Granger, C.A.

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Exploring nutritional therapy practitioner perspectives on working with people affected by cancer

Carol Anne Granger

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Abstract

Introduction

Nutrition can impact significantly on cancer occurrence, recurrence and survival. Many people affected by cancer seek individualised nutrition advice, but globally this remains an unmet need for many. Nutritional therapy (NT) practitioners provide personalised nutritional care, including complementary care for people affected by cancer. Until now, there is little documentation internationally of NT practice with people affected by cancer. This mixed methods study explores NT practitioners' perspectives, to inform professional development needs to ensure safe evidence-based practice with people affected by cancer.

Methods

An on-line anonymised survey was open to all UK registered NT practitioners. Data was collected on practitioner characteristics, patterns of practice with people affected by cancer and perceived barriers to that practice, the use of research evidence in practice, and practitioners' perceived needs for training and support. Data on practitioner characteristics were compared between practitioners who work with people affected by cancer (CP) and those who do (NCP). Preliminary themes emerging from the survey informed the second phase, in which semi-structured individual interviews (n=21) and one group interview were used for in depth exploration of practitioner perspectives on practice with people affected by cancer. Topics explored included rewards and motivation, barriers and challenges to practice, and professional development needs. Interview transcripts were analysed thematically, using Framework methodology.

Results

274/888 (31%) UK registrants completed the survey. CPs were more likely than NCPs to have additional health and life science (HLS) qualifications ($p=0.009$) and to have been in practice for longer (practice for more than 10 years, $p=0.012$). 80% survey respondents overall, including CPs, worked alone for at least some of the time. Practitioners experienced reward in empowering people affected by cancer to make dietary changes, for some their own cancer journey or witnessing cancer in a loved one was a motivator. Significant challenges and barriers to practice included managing the emotional and psychological demands of working with people affected by cancer, lack of recognised specialist training and resources, and lack of engagement with or perceived opposition from oncologists. To overcome these barriers, professional development needs identified were firstly specialist clinical supervision, mentoring and networking to overcome isolation and share best practice. Secondly, specialist training and resources to facilitate accessing, critically appraising and communicating evidence in practice are required. Thirdly, engagement with mainstream professionals working in cancer care requires improvement.

Conclusions

This is first detailed exploration of NT practitioner perspectives on working with people affected by cancer and the data have revealed important areas for developing training and support. Findings are informing development of frameworks for practitioner support including clinical supervision and specialist training, to support safe evidence-based practice and better communication and integration with mainstream cancer care. Future exploration of NT practitioners' perspectives should assess the impact of proposed professional developments highlighted here. Further exploration of perspectives of mainstream healthcare professionals with whom nutritional therapy practitioners may engage is also recommended.

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Abbreviations

AfN - Association for Nutrition
 BANT – British Association for Applied Nutrition and Nutritional Therapy
 CAM – Complementary & Alternative Medicine
 CNHC - Complementary and Natural Healthcare Council
 CP – Cancer Practitioner
 EPIC - European Prospective Investigation of Cancer and Nutrition study,
 HLS – Health and life sciences
 IGF-1 – Insulin like growth factor-1
 NCP – Non Cancer Practitioner
 NHS - National Health Service
 NOS – National Occupational Standards
 NT - Nutritional Therapy
 NTEC – Nutritional Therapy Education Commission
 NTC – Nutritional Therapy Council
 UKVRN - UK Voluntary Register of Nutritionists

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Author's Declaration

I declare that all the material contained in this thesis is my own work

Chapter 1. Background information and literature review

1.1 Introduction

This chapter provides the context for this doctoral study, which explored a previously undocumented area of professional activity in the care of people affected by cancer. The theoretical and reflexive perspectives of the professional doctorate researcher undertaking this research, which influenced the direction and design of the study, are defined at the end of this opening section.

This chapter describes the nutritional therapy (NT) profession and its training and regulatory frameworks. The profession is then differentiated from other nutrition professions, providing context for the position of the NT profession in UK healthcare. Cancer as a global health burden will then be summarised, identifying some known contributing factors that may be modifiable. The relevance of nutrition for people affected by cancer is then outlined, and the extent of the evidence base is discussed, highlighting relevant areas of uncertainty. The complexity of nutrition evidence will be illustrated by examples of research findings for common dietary components, and sources of uncertainty inherent in nutrition evidence will be discussed. The framework for cancer care in the UK is outlined and the current provision of nutrition advice for people affected by cancer is described, identifying questions with regard to advice from NT practitioners. Previously undocumented areas of knowledge with regards to NT practice and their implications for patient care are identified. The design of some studies that have explored use of evidence in healthcare, and relationships between healthcare professions are discussed in the context of informing the design of this research. Finally the rationale for this research is summarised.

This study has been conducted by a researcher whose ontological and epistemological perspectives are influenced by four professional domains. Firstly as a NT practitioner working with people affected by cancer, her experience situates her as a professional insider, which is discussed further

in section 2.7. Secondly, her previous career in biosciences provides a backdrop of close alignment with mainstream healthcare and evidence-based practice. Thirdly, as chair of the NT training accreditation body, there is particular interest in standards of training for the profession. Finally, this researcher has specific commitment to professional regulation and served on the working group that established the Complementary and Natural Healthcare Council (CNHC) and on the first professional board for NT within the CNHC. These four domains served as points of reference for reflection during the design, execution and completion of the study. The literature review informing the study design is therefore also framed by these perspectives, to encompass the literature on nutrition evidence in cancer practice, training, professional regulation and the role of the practitioner-researcher.

1.2 The NT profession

This section introduces the NT profession, attempts to differentiate it from other related professions and comments on relationships with those other professions.

NT is a bioscience-based practice (Granger and Watkins, 2014) but also draws on a body of evidence from a number of disciplines, including anthropology, epidemiology, public health, clinical medicine, and *in vivo* and *in vitro* nutrition science. NT practitioners, generally referred to as nutritional therapists, are trained to work with healthy individuals and those with health problems to provide personalised nutritional counselling (Complementary & Natural Healthcare Council, 2017). This comprises dietary recommendations, supported where necessary by nutritional supplements, in order to prevent disease and optimise health. The basis of NT is that each individual has unique nutritional requirements (Koithan and Devika, 2010) determined by a number of factors; including genetics (Ziegler et al., 2002), lifestyle, environmental exposures and life events; and that nutritional intake and other health choices (such as physical activity) can impact on the expression of the

individual's inherited constitution (Mathers, 2008, Supic et al., 2013). The approach of NT practitioners to this interaction of genetics and potentially modifiable risks is therefore to assess the client and counsel on appropriate levels and sources of nutrients, providing a personalised nutritional plan (Complementary & Natural Healthcare Council, 2017, Skills for Health, 2010c, Granger and Watkins, 2014). Genetic information may also be considered in a personalised nutrition plan by some NT practitioners (Richardson and Mason, 2011, Benbow et al., 2017) and may incorporate analysis of specific genes associated with nutritional function, such as those governing fat metabolism (Hesketh, 2013) or folate metabolism (Ragasudha et al., 2012, Huang et al., 2012, Wernimont et al., 2012, Powers, 2005).

Training in nutritional therapy to the National Occupational Standards (NOS) at diploma, Bachelor's degree and Masters' degree levels is accredited by the Nutritional Therapy Education Commission (NTEC) (Nutritional Therapy Education Commission, 2017, Benbow et al., 2017). Courses meeting the NOS have been running since 2000 (Complementary & Natural Healthcare Council, 2016), and include the study of anatomy, physiology, biochemistry, nutrition science, dietary models, behaviour change, safe appropriate use of nutritional supplements, and compulsory clinical training at academic level 6 which includes reflective practice (Nutritional Therapy Education Commission, 2017). Courses taught at post-graduate level may have an element of clinical specialisation, but the aim of training to the NOS is to produce competent generalists (Nutritional Therapy Education Commission, 2017) and there is no formal framework for post-qualification training.

There is also voluntary practitioner registration with the Complementary and Natural Healthcare Council (CNHC) and there are currently about 800 NT practitioners on the Professional Standards Authority (PSA) Accredited Register held by the CNHC (CNHC personal communication). Registration requires demonstration of working at the NOS, either by qualification from an NTEC accredited course, or by completion of an Accreditation of Prior Learning portfolio (Granger and Watkins, 2014, Complementary & Natural Healthcare Council, 2017). A number of professional associations have

nutritional therapists amongst their membership, with the British Association for Applied Nutrition and Nutritional Therapy (BANT) representing practitioners who demonstrate working at the level of the NOS, are insured and registered with the CNHC (BANT, 2014).

1.2.1 Relationship to other nutrition professions

NT practitioners are one group of professionals amongst many that may provide nutrition advice and information, to individuals and groups of people, in a variety of settings. There are areas of commonality in practice between three identifiable nutrition professional groups, which are: dietitians, nutritionists and nutritional therapists. All three professional groups can base their practice on a common landscape of evidence, but a degree of professional differentiation exists, which is explained below, to clearly delineate the profession group that has been studied in this doctoral project.

The dietetic profession, which is said to have emerged from nurses interested in nutrition, has been formally present in the UK for almost a century (Hutchinson, 1961), since the establishment of the first department of dietetics in Edinburgh Royal Infirmary in 1924. UK Dietitians are trained to Bachelor's degree or post-graduate level, and are regulated by statute by the Health and Care Professions Council (HCPC) (Health and Care Professions Council, 2012). Dietitians, whose professional title is protected by statute, work in healthcare and other roles, providing dietary advice and nutrition information, contributing to clinical care, health promotion and public information. Dietetic practice is established in, and integrated into care pathways in primary and hospital care and in the community, and includes clinical nutrition support measures such as naso-gastric or intravenous administration of nutrients that supplement or replace oral intake (Selwood et al., 2010), interventions which may be referred to as Nutrition Therapy, Medical Nutrition Therapy or Nutrition Support Therapy (Cederholm et al.,

2017). This terminology is noted here to differentiate it from NT, the practice of which is the subject of this doctoral thesis.

In addition to NT practitioners and dietitians, a third group of nutrition professionals are referred to as nutritionists, although this term may be used by a wide range of practitioners with variable levels and types of training (Granger and Watkins, 2014). Graduates with a nutrition degree may apply to be registered with the Association for Nutrition (AfN) in the UK Voluntary Register of Nutritionists (UKVRN) (Association for Nutrition, 2017). UKVRN registrants may work across a range of sectors including the food industry, animal nutrition, sports nutrition, public health and research, and may provide nutrition advice to healthy individuals. They may work with individual clients to improve an identified health condition if supervised by a healthcare practitioner that is subject to statutory regulation; generally a medical practitioner or dietitian (Association for Nutrition, 2013). AfN accreditation of nutrition degree courses does not require compulsory clinical training (Association for Nutrition, 2016), unlike accredited NT courses. Within the UK there are established academic departments of nutrition, a learned society (the Nutrition Society) which gave rise to the AfN, and peer-reviewed nutrition journals dating from the 1940's, reflecting the history of research in nutrition science and application (Copping, 1978).

Overlap in occupational function and professional tension exists between these three professional groups, evident in some public communications and publications, reflecting competition between professions seeking to occupy a common area of work and influence. The NT profession exists independently of the National Health Service, and the provision and standards of training and practice of the NT profession have been questioned in publications by dietitians (Murphy and Girot, 2013) and nutritionists (Cade et al., 2012). The British Dietetic Association, which represents UK dietitians, has claimed that NT practice is not evidence-based or regulated (British Dietetic Association, 2014). To consider this inter-professional tension in the context of the literature on contested professional boundaries in healthcare (King et al., 2015), tension between professional groups may take place where professional territories are perceived to be threatened, where established

professions seek to defend their role against the entry of newer professional groups. King's (2015) review examined seven examples of boundary disputes between professional groups including medical, nursing, other allied health professions and some CAM professions. They included horizontal boundary contests, where a new group seeks to act in equivalence with an established profession, and vertical boundary disputes where an area of practice was taken on by a group with usually a lower level of skills, such as some nursing tasks taken on by healthcare assistants. Horizontal boundary challenges were reported to invoke hostility, to involve strategies such as discrediting the usurper group and by redefining the contested role, and were less likely to be resolved by negotiation (King et al., 2015). It could be argued, however, in the tension between the three nutrition professions described in this section, that established professions refer to their academic heritage in defending their professional status when faced with competition from a less established professional group.

Despite the existence of accredited training and voluntary regulation of both nutritionists and NT practitioners as well as statutory regulation of dietitians, unregulated individuals with training of unknown standards can also provide nutrition advice (Granger and Watkins, 2014). Unregulated individuals may use a variety of titles such as nutritionist, nutritional therapist, nutrition adviser, or dietary advisor, since only the professional title of dietitian is protected by statute. The number of such unregistered 'nutrition practitioners' is not documented. Moreover, a number of other complementary and alternative medicine (CAM) practitioners, including naturopaths and herbalists, may also give dietary advice to their clients, as defined by their NOS (Skills for Health, 2010a, Skills for Health, 2010b).

In summary, the NT profession operates independently of the UK National Health Service and is the newest of three defined nutrition professions that may provide advice to individuals and groups. Dietitians are integrated into mainstream healthcare provision and regulated by statute with protected professional title, NT practitioners and nutritionists are subject to voluntary regulation and training accreditation. Occupational and training standards for all three are publicly defined, under which all three professions may provide

nutrition advice to healthy people. NT practitioners and dietitians may work independently with people with health conditions, and nutritionists may do also but only under the direction of statutory-regulated professional. Tension and competition exists particularly between the NT profession and the other two professions. Beyond these nutrition professionals, there is an unknown number of variably trained and unregulated individuals, and other CAM professions, who may provide nutrition information to individuals and groups.

There are therefore three specific issues regarding the nutritional therapy profession that this research addresses. Firstly, the potential for isolation, both at a professional and practitioner level, since the profession operates independently, outside of mainstream healthcare provision within the UK. Secondly, training for working with people affected by cancer, since the current accreditation framework defines training up to the point of qualification as generalist NT practitioners. Finally, also related to the separation of the profession from mainstream professions, the question of relationships and communication with other professions, to ensure safe, effective practice for people affected by cancer.

1.3 The relevance of nutrition for people affected by cancer

This section will firstly define cancer and outline some contributing factors that may be modifiable including diet and lifestyle, to establish the relevance for nutrition professionals to work in this area of human health. This concurs also with the reflexive perspective of this researcher that healthcare practice should be underpinned by evidence. The literature reviewed encompasses evidence of relevance to nutritional therapy practice, that is, nutrition of ambulatory people in the community. It does not consider in-patient nutrition, or dietetic nutrition support measures such as enteral feeding that may be used in the care of some people affected by cancer, or aspects of nutrition relating to end of life care for people with cancer.

To provide context for nutrition as a factor in the incidence of cancer, the relative impact of some other notable modifiable factors is contrasted with data for some dietary components. The extent of evidence for the impact of

nutrition in preventing cancer occurring (primary prevention) or recurring (secondary prevention) will be outlined. This section will illustrate that interpreting evidence to formulate advice for people affected by cancer is complex, and a challenge for nutrition professionals aiming to provide evidence-based advice.

1.3.1 Cancer as a major global health challenge

Cancers are a leading cause of death worldwide, responsible for 14.1 million new cases and 8.1 million deaths globally in 2012 (Torre et al., 2015). Malignancy can develop potentially in all human organs and tissues, is characterised by abnormal cell division, proliferation and spread, and involves genetic and epigenetic changes which result in changes to the processes controlling cell behaviour (Kreeger and Lauffenburger, 2010). For some cancers, a pre-malignant stage is recognised, which represents an increased risk of developed frank malignancy, for example Barrett's oesophagus, which predisposes to oesophageal cancer (Kubo et al., 2010) and bowel polyps which predispose to colorectal cancer (Higurashi et al., 2016). Genetic predisposition is recognised for some cancers, for example, some inherited gene mutations are associated with a lifetime risk of developing breast cancer of up to 60% for women carrying mutations in the BRCA genes (Parkes et al., 2017), compared with a population average lifetime risk of developing breast cancer of 12% for women in the UK (Godley et al., 2017).

As well as genetic factors, which overall account for 5-10% of all cancers (Parkin, 2011a), a number of modifiable risk factors have been identified which vary considerably between cancer types and will be outlined here, to provide perspective on the potential role of nutrition and lifestyle in cancer. A detailed study of cancers in the UK assessed the relative contributions of fourteen potentially modifiable factors (Parkin, 2011a). This examined meta-analyses and systematic reviews of up to fifteen years of data on occupational and environmental exposures, infection, hormonal exposures, diet, alcohol, smoking, obesity and physical inactivity, to estimate the

contribution of each risk factor to new cancers occurring in 2010 in the UK. Risks were assessed against the recommended exposure levels of each factor – tobacco exposure is recommended to be nil, for example, and some factors were quantified, such as the increased risk of developing cancer per gram of alcohol consumed per day, compared with no alcohol consumed. Overall, the fourteen risk factors studied were estimated to be responsible for approximately 134000 new cases of cancer in the UK that year, which accounted for 45.3% of cancers in men and 40.1% cancers in women, 42.7% overall, and 50% cancer deaths (Peto, 2011). To illustrate the range of impact of the risk factors studied, it was estimated that 86% new cases of melanoma skin cancers in the UK in 2010 were attributable to solar radiation exposure, and this constituted 3.5% of all new cancers in the UK in that year (Parkin et al., 2011). In contrast, occupational exposures to compounds such as asbestos and mineral oils, and shift-work, were responsible for 3.7% of all new cancers that year, but this figure excluded skin cancers arising from occupational sun exposure (Parkin, 2011d). Exposure to tobacco smoke was estimated to have contributed to 86% new cases of lung cancer (Parkin, 2011b), whereas alcohol was estimated to have contributed to 3.6% all new cancers in 2010, including cancers of the mouth, pharynx, oesophagus, breast, liver, colon and rectum (Parkin, 2011c). The confounding effects of combining several risk factors were taken into account in the analysis. These figures, which reflect a considerable health burden, illustrate firstly the complexity of cancer risk, in that an individual may have multiple exposures, and secondly that the relative impact of risk varies widely between factors. As a lifestyle exposure, tobacco smoking stands out as carrying a considerably greater risk than several dietary factors, which will now be discussed.

1.3.2 The impact of nutrition on cancer risk – role in primary prevention

Having illustrated the contribution to the national cancer burden of modifiable risks such as smoking tobacco and consuming alcohol, this section will discuss the extent and types of evidence on the impact of nutritional factors

on primary cancer risk. The relevance of this is firstly to illustrate the complexity of data on the relationship between nutrition and the risk of cancer, particularly when considering the interpretation for individuals of data derived mostly from studies of populations. This complexity is illustrated with examples of evidence on the interconnected impact of different dietary components, and with the contrary data on cancer risks associated with consuming dairy products. Primary cancer prevention could be considered of relevance for all individuals, including for those with perceived or actual greater cancer risk due to family history, lifestyle or pre-disposing condition, for example people affected by Barrett's oesophagus who are at greater risk of developing oesophageal cancer (Kubo et al., 2010). Secondly, people living with and beyond cancer are recommended to follow diet and lifestyle advice for primary prevention where there is no specific evidence on preventing cancer recurrence (Rock et al., 2012), therefore the evidence reviewed in this section has relevance for people affected by cancer seeking advice on modifiable risks for cancer recurrence.

The European Prospective Investigation of Cancer and Nutrition (EPIC) study, of half a million individuals across 10 countries, prospectively investigated the population impact of specific food groups and patterns on the incidence of different cancers and attempted to relate these to some mechanisms that may underlie those effects (Gonzalez and Riboli, 2010). The EPIC consortium used a variety of data collection methods across and within the national populations studied, including reference to national cancer registries, collection of anthropometric data, assay of some nutritional biomarkers, and participant dietary records as food frequency questionnaires (Riboli, 1997). From this data, which was reported for individual national cohorts and pooled as a cross-Europe analyses, intake of specific food groups and adherence to dietary patterns were assessed for their impact on site-specific cancers. Overall, the study concluded that dietary modifications - such as lower intakes of meat (Gonzalez and Riboli, 2010) and alcohol (Sieri et al., 2002) and increased consumption of dietary fibre (Bingham et al., 2003), vegetables and fruit (Boffetta et al., 2010) - could reduce the incidence of several types of cancers and quantified the impact of some of

these dietary factors. For example, the incidence of colorectal cancer was 35% higher in those consuming 160g of red and processed meat per day, compared with those consuming less than 20g/day (Gonzalez and Riboli, 2010). Dietary fibre intake was inversely associated with risk of developing colorectal cancers, with a relative risk of 0.58 for consumers of 35g fibre per day compared with 15g/day (Gonzalez and Riboli, 2010), and was estimated that if the fibre intake of those in the lowest quintile of fibre intake was increased to that of the highest quintile, the risk of colorectal cancer could be reduced by 40% (Bingham et al., 2003). Dietary fibre reduces the risk of several gastrointestinal cancers by multifactorial mechanisms, including more rapid gut transit time which reduces carcinogen exposure, improved weight control due to increased satiety, and the presence of several micronutrients such as phytic acid which appear to have specific protective effects against DNA damage (Fardet, 2010).

More modest reductions in risks of colorectal cancer were ascribed to intake of vegetables and fruit, with a relative risk of 0.97 for those consuming an additional 200g/day of vegetables and fruit (Boffetta et al., 2010). Illustrating the potential for interactions of modifiable cancer risks within an individual's dietary intake, the adverse impact of low dietary fibre intake was compounded by higher red and processed meat intake (Gonzalez and Riboli, 2010).

The interconnected or synergetic effects of several dietary components were further investigated within the EPIC study by assessment of the impact of dietary pattern (Gonzalez and Riboli, 2010). Adherence to the Mediterranean diet, which includes fish, vegetables, fruit, nuts, legumes, wholegrains and olive oil, was measured on a scale of 0-9, and the hazard ratio of developing any cancer was determined as 0.96 for a two-point increment on the scale (Couto et al., 2011). Cancer site-specific data within this analysis reported that the risk of stomach cancer was reduced by 5% for each 1-point increment in adherence to the Mediterranean diet (Buckland et al., 2010). For dietary components such as dietary fibre and fruit and vegetables, there is evidence of benefit across several cancer types (Gonzalez and Riboli, 2010). There are, however, data for other dietary components suggesting variable or even contrary effects on the risks of developing different cancers,

again demonstrating the complexity of evidence available to nutrition professionals. The evidence on cancer risks and dairy products illustrates this: the EPIC study concluded that the incidence of colorectal cancer was inversely associated with the intake of dairy products (Murphy et al., 2013). Within that analysis, association with different types and fat content of dairy foods was scrutinised, and the protective effect was reported to be consistent across all dairy products, and purported to be related to dietary calcium. Furthermore, an international systematic review and meta-analysis by the World Cancer Research Fund (WCRF), of 19 cohort studies (Aune et al., 2012), concurred with the conclusions of EPIC on the protective effects of dairy foods except cheese, reporting a relative risk of 0.83 per 400g total dairy produce consumed per day, and 0.91 per 200g milk per day. In contrast with the reported protective effect of consuming dairy produce on colorectal cancer risk, however, higher dairy product intake was reported to be linked to increased risk of prostate cancer within the EPIC study (Gonzalez and Riboli, 2010). This finding was reinforced by a later WCRF systematic review of 32 studies (Aune et al., 2015). A recent systematic review and meta-analysis of 172 studies of the association between dairy produce intake and prostate cancer (Harrison et al., 2017) identified a role for raised insulin-like growth factor (IGF) in prostate cancer development, reporting increased IGF activity with higher consumption of dairy products, specifically milk.

For breast cancer, however, the data is more complex – for instance, a case control study of 275 women in Iran reported decreased levels of breast cancer with high total intake of dairy product and of low fat fermented dairy products, but an increased risk with high intakes of high fat dairy products (Bahadoran et al., 2013). This effect may be linked to increased body fat in consumers, or due to the presence of oestrogen or other growth factors in milk products (Daxenberger et al., 2001); there may also be specific effects of saturated fat, or increased systemic inflammation (Esmailzadeh and Azadbakht, 2010). Conversely, a larger Chinese case-control study (438 women) reported no association between breast cancer incidence and total intake of dairy foods, but protection appeared to be afforded by high dietary calcium intake (Zhang et al., 2011). A number of differences may explain these discordant results; genetic differences between populations,

differences between dairy (and other) foods consumed, and methodological differences, since both used Food Frequency Questionnaires but with differences on the composition of the food categories. Study design may also have an impact on results, in that case-control studies examining the relationship between diet and disease are considered to be prone to dietary recall bias by study participants (Gibson et al., 2010). This is because data is usually collected retrospectively and after diagnosis of the condition being studied. In contrast, prospective cohort studies avoid this bias, but are potentially prone to loss to follow-up of study participants over the duration of the study (Gibson et al., 2010). In light of discordant findings for dairy produce and cancer risk, a meta-analysis of 18 prospective cohort studies of over a million women was conducted (Dong et al., 2011), which concluded that some protection against the risk of developing breast cancer was associated with increased dairy intake when total dairy intake was considered, but the protective effect was not seen when milk alone was considered. These data on the impact of one food group on the risks of colorectal, prostate and breast cancers demonstrate that relationships between dietary intakes and cancer risk are complex. Furthermore, prospective studies such as EPIC collected data across geographically, culturally and genetically diverse populations (Gonzalez and Riboli, 2010). The inherent complexity in nutrition evidence will be further explored in section 1.4.

Apart from the impact of individual nutritional components or dietary patterns, other studies have demonstrated that nutritional intakes may influence the risks of many common cancers in part through impact on body mass and particularly levels of body fat (adiposity) (Hursting and Hursting, 2012). In the aforementioned national study of fourteen risk factors contributing to UK cancers (Parkin and Boyd, 2011), it was estimated that 5.5% of all new cancer cases in the UK were attributable to overweight, defined as body mass index (BMI) over 25 kg/m². There was variation in impact of body weight between different cancer types within Parkin's (2011) study; for example, for women, 8.7% breast cancers and 33.7% endometrial cancers, and 26.7% oesophageal cancer in men, were attributed to overweight. A

number of studies have attempted to elucidate the mechanisms underlying the relationship between cancer, nutrition and higher body mass: obesity and increased levels of visceral or abdominal fat are linked to inflammation and to raised insulin and insulin-like growth factor (IGF-1) levels, which display tumour-promoting behaviour, leading to tumour growth and spread (Doyle et al., 2012). For example, raised levels of insulin and specifically insulin-resistance in women appear to be associated with significantly increased risks of developing cancer of the breast, ovary and endometrium (Sun et al., 2016). Insulin and IGF-1 activity can be influenced by diet (Runchey et al., 2012, Freedland et al., 2008, Heiss et al., 2017) and by levels of physical activity (Haydon et al., 2006). These data illustrate therefore that diet has a complex and multifactorial relationship with cancer risk, through individual components, through dietary patterns, and through influence on body weight and adiposity.

In summary, therefore, the evidence on the relationships between dietary patterns, foods and food components and the risk of developing cancer is complex. Dietary components may have an individual impact on cancer risk or act in synergy with others, so that dietary pattern is also relevant, and some foods appear to be protective against one cancer type whilst increasing the risk of another. Impact of diet on body weight and body composition also has relevance for cancer risk. Studies of populations provide data to inform primary cancer prevention, furthermore, for people living with and beyond cancer, the advice is to consider the data for primary cancer prevention where no definitive advice for secondary prevention exists (World Cancer Research Fund/American Institute for Cancer Research, 2007, Inoue-Choi et al., 2013).

1.3.3 Evidence on nutrition and secondary prevention of cancer

Having demonstrated that the evidence on primary cancer prevention is complex and incomplete, this section will demonstrate that there is complexity and gaps in the evidence on dietary choices for people seeking to

avoid progression or recurrence of cancer. As previously noted, cancer survivors are advised by bodies such as WCRF to follow guidance for primary prevention in the absence of definitive evidence on secondary prevention. Prospective trials of lifestyle interventions incorporating exercise and dietary change with people affected by cancer suggest overall that physical activity and weight loss may decrease risks of cancer progression and recurrence, and therefore positively impact on life expectancy (Pekmezi and Demark-Wahnefried, 2010, Inoue-Choi et al., 2013). A review for the UK National Cancer Survivorship Initiative (NCSI) considered 43 studies of the relationships between diet and exercise versus recurrence and progression of breast, prostate and colorectal cancer (Davies et al., 2011). This included prospective observational studies of cancer survivors, and randomised trials of dietary interventions, such as reduced fat intake in the Women's Intervention Nutrition Study (WINS), which reported reduced recurrence and progression of breast cancer with lower dietary fat intake (Chlebowski et al., 2006). Overall, the NCSI review concluded that, despite the lack of definitive trials, that maintaining healthy body weight, regular physical activity and adherence to diets high in fibre and low in fat, may offer some reduction in cancer recurrence and progression (Davies et al., 2011). This and later studies have suggested that the mechanisms involved may include influencing inflammation, insulin and IGF-1 (Davies et al., 2011, Hursting and Hursting, 2012, Al-Wahab et al., 2014, Ferroni et al., 2016). The interconnected effects of diet and lifestyle seen in the primary cancer prevention data are again seen in the data on secondary prevention. For example in a review of lifestyle factors affecting breast cancer survival in young women (Brenner et al., 2016), consuming food in excess of the body's energy requirements (positive energy balance) and dietary patterns leading to inflammation were considered to act together to promote cancer recurrence and progression, and reduce survival. The impact of excess body weight may have negative consequences on people living with and beyond cancer in addition to tumour-promoting metabolic effects, for example, obese men with prostate cancer present technically greater surgical challenges than non-obese men, they benefit less from androgen-deprivation therapy

and are more likely to have more aggressive disease (Stewart and Freedland, 2011).

To further demonstrate complexity in nutrition evidence, randomised studies of dietary interventions designed to test hypotheses from observational studies may provide contradictory or confounding evidence. For example, population studies such as EPIC reported a higher dietary fibre intake is associated with lower colorectal cancer risk (Bingham et al., 2003), but a Cochrane review of prospective trials of dietary fibre in bowel cancer survivors found no improvement in survival with higher fibre intakes (Yao et al., 2017). The highest fibre intake group actually had slightly increased risk of cancer recurrence compared with controls, albeit an increased absolute risk of only 1%. This contrary finding underlines that primary cancer prevention data may not always be translated into benefits in secondary cancer prevention.

In summary, there are gaps in the evidence on secondary cancer prevention. Current evidence from population and pilot studies and informed by laboratory investigations, suggests that nutrition may influence recurrence and progression of several common cancers, partially through impact on body weight, but also on inflammation and insulin. There have been few intervention studies, and the evidence on the impact of individual dietary components such as dairy produce is not clear. Deriving advice for individuals from the evidence base in some areas is challenging, requiring interpretation of complex and sometimes conflicting data.

1.4 The use of evidence in NT practice

Having established that there is evidence that nutrition may influence the development, progression and recurrence of several cancers, but that there are gaps and complexity in the evidence, this section will discuss the challenges of applying evidence to inform appropriate individual advice for people affected by cancer. The application of the model of evidence-based healthcare to nutrition is considered and challenges to its use in practice are

discussed. The contrast between guideline-centred care and the emergence of precision cancer care and patient-centred care is discussed. The question of the use of evidence in NT practice, which is based on biochemical individuality, for people affected by cancer, is explored.

Evidence, the findings from systematic research, may be used to inform healthcare practice in a number of ways. Evidence-based medicine (EBM) as a paradigm was developed to inform healthcare policy and support best practice (Greenhalgh et al., 2014). EBM is based on the development and application of the most robust research evidence, and recognises a hierarchy of evidence based on study design. For example case reports and 'expert opinion' are on the lower levels of the hierarchy, whereas evidence from double-blind randomised controlled trials (RCT) would be considered more robust as a basis for practice (OCEBM Levels of Evidence Working Group, 2011). RCTs represent evidence collected for large numbers of individuals, to test the potential effects of defined interventions. RCT study designs control for placebo effect, human variation, and potential confounding factors. Systematic reviews and meta-analyses of RCTs are at the top of the evidence hierarchy, and considered to be the most robust basis for producing standardised clinical practice guidelines (OCEBM Levels of Evidence Working Group, 2011). Evidence-based nutrition (EBN), modelled on evidence-based medicine, similarly looks to use the most robust evidence to guide nutrition practice (Mann, 2010). However, it is recognised that unlike studies of drugs which generally are single compounds, RCTs are not always suitable for studying nutritional interventions (Blumberg et al., 2010) and particularly for conditions such as cancers which take many years to develop (Mann, 2010). Individual preparations or combinations of nutrients in the form of supplements have been studied in RCTs for cancer prevention (Myung et al., 2010), but frequently show no effect on cancer risk and sometimes provide contradictory results when compared to observational data. For example beta-carotene supplements increased the incidence of lung cancer in smokers in the CARET trial, whereas epidemiological data reported that dietary carotenoid intake was associated with lower rates of lung cancer (Fritz et al., 2011). This may be due in part to differences between the

supplement used in the trial and the form and concentration of the natural nutrient in the diet. The CARET study illustrates the potential risks of assuming that evidence from population studies of diet would be translated into the same effect for an intervention with an isolated supplement.

The effects of individual nutritional supplements can therefore be studied in large RCTs, but there are considerable challenges in conducting RCTs with diets. In contrast with defined nutritional supplements, diets and even individual foods present challenges to the use of RCTs. Firstly, single foods (e.g. egg) are often complexes of several types of compounds and may be subject to natural variation which may affect the level of nutrients (Anderson, 2011, Anderson, 2013); single nutrients may occur in several forms (e.g. vitamin E), and nutrients often have multiple complex effects in the body (Peh et al., 2016). Secondly, food and dietary patterns are more complex than individual nutrients, for example as previously discussed, the specific dietary pattern defined as the Mediterranean diet may have an impact on cancer risk (Buckland et al., 2010, Buckland et al., 2009, Trichopoulou et al., 2009). Thirdly, RCTs are not suited to measure complex human biological variation or long term effects (Mitchell et al., 2011) and also there would be ethical issues in the use of intentional nutrient deprivation in a control group.

Therefore in the absence of unequivocal human trial data, other types of evidence may be considered. For example, non-randomised trials (Gaus and Muche, 2013), observational studies, studies of biomarkers of cellular processes, and evidence of biological mechanisms for nutritional components, may be also considered acceptable as evidence for the effects of specific nutritional interventions (Mitchell et al., 2011). Finally, it has been argued that the weight attached to evidence from RCTs, considered near the top of the evidence hierarchy, should be tempered by consideration of the biological mechanisms of the effect studied. This is because positive RCT data in the absence of a plausible mechanism for the apparent effect should call into question the external validity of the study (Clarke et al., 2012).

It has been proposed by some nutrition researchers therefore that the practice of EBN should be based on the totality of evidence (Blumberg et al.,

2010). Public health nutrition policy, which seeks to improve the health of populations, may draw on a range of data including epidemiological and prospective studies (Slavin, 2015, Maki et al., 2014), which are used to formulate guidance on cancer prevention from bodies such as WCRF (Inoue-Choi et al., 2013, Norat et al., 2014). However, where evidence is incomplete or contradictory, it has been suggested that the risks associated with nutritional interventions should be considered, such that the level of evidence required to support an intervention would be proportionate to the potential for harm (Broom et al., 2009, Arnold, 2011). Similarly it has also been proposed that in formulating nutrition guidance for cancer prevention (Gonzales et al., 2014), that the precautionary principle is applied. This principle is applied in blood transfusion medicine (Kramer et al., 2017) and toxicology (Gonzales et al., 2014), for example, when considering the potential risks of exposures, and means that if there are reasonable grounds for concern they should be considered even when there is no definitive evidence or the evidence cannot be collected. For example, applying this principle for nutritional supplements would consider the potential for risk in the absence of specific evidence of benefit or harm.

Applying evidence-based healthcare that uses data from large numbers of people to produce policy and guidance for clinical practice with individuals may have a number of shortcomings (Greenhalgh et al., 2014). Firstly adherence to guidelines may be at odds with patient-centred care. Secondly results from large tightly controlled research trials represent an average response within trial conditions that does not account for the range of individual responses in real life (Greenhalgh et al., 2014). In the field of nutrition, a critique of the use of EBN knowledge in practice identified that the emphasis on 'objective evidence' is often contrary to the needs of the end-user of information, the client/patient (Cornelissen et al., 2011). A case is made by Cornelissen (2011) for balance between client-centred information and evidence-based knowledge, particularly where the evidence is incomplete or contradictory, and where the client's needs are complex. Although evidence-based healthcare is claimed to remove clinicians' subjective judgement from treatment choice, the selection and analysis of

evidence used to produce guidelines are framed within a social context and values (Kerridge, 2010). Furthermore, it has been argued that imposing standard practice in cancer care based on 'best evidence' reduces the need for clinicians to assess evidence for individual cases, which may remove autonomy from professionals and reduce the need for skills in critical appraisal (Broom et al., 2009). Finally, the development of precision cancer medicine, where treatments are selected based on individual cancer biomarkers and tumour genetics (Jackson and Chester, 2015) is already influencing clinical practice (Berger and Van Allen, 2016). This is exemplified in the treatment of patients affected by non-small cell lung cancers where specific tumour genetic characteristics determine the choice of treatment (Xu et al., 2017). The overall direction on new developments in the care of people affected by cancer in well-resourced countries appears to be moving towards precision or even individualised treatments for several types of cancer, as opposed to broadly applied standardised protocols (Schram et al., 2017).

To summarise, evidence generated by observational studies of the associations between nutrition and cancers and some trials of nutrition interventions provide a landscape of evidence within which there are gaps. The nature of human nutrition is complex, multifactorial and subject to natural variation in foodstuffs and human individuals, which presents challenges to the use of single interventions studies modelled on evidence-base medicine. In the absence of decisive data from RCTs other types of evidence may inform nutrition advice for populations and individuals. In this context, therefore, the use of evidence in NT practice, which is based on biochemical individuality and personalized care, has not been documented until now, and NT practitioners' perspectives on the use of 'evidence' deserves scrutiny.

1.4.1 Researching the use of evidence in practice

In this section, aspects of study design emerging from research of the use of evidence in healthcare practice are discussed, with respect to their relevance for this doctoral study. Since research utilisation in practice has not been

previously explored for the NT profession, research with other healthcare professions may provide some useful perspectives. Studies of the use of research in healthcare have used a number of approaches, for example; Canadian and Swedish nurses' perspectives on the use of research were explored (Estabrooks et al., 2011) using a qualitative approach of three iterative phases of focus groups of firstly local experts, then international experts, and finally practicing nurses. Estabrooks (2011) data revealed that nurses' understanding of the concept of 'research utilisation' in practice is complex, including different uses of terminology, where 'information', 'evidence' and 'research' were all terms used by nurses to refer to evidence from research that may inform clinical practice. It was concluded that practitioners' understanding of research was a multi-faceted construct and this should be considered when designing studies to measure research utilisation by nurses. In a UK study, accessing and interpreting the evidence base by 242 nurses over a period of five years was explored by interviews, observation, and clinical document audit (Thompson, 2003, Thompson et al., 2004). Results revealed that nurses preferred human sources of information rather than consulting written material. Nurse specialists and pharmacists were consulted for specialist information more often than published data, because nurses perceived they provided context-specific advice upon which to base their practice, although formal written hospital guidelines were also consulted. Thompson's (2004) work examined information sourcing in multidisciplinary healthcare settings, however, NT practitioners working independently may have less access to 'experts' to confer with. Therefore, it was important in this research, to examine practitioners' perspectives on the use of 'evidence' and other types of information. It was also important to explore their opportunities for interactions with other practitioners from whom evidence and other types of information may be sought.

In summary, nutrition evidence is complex and incomplete for cancer. The perspectives of NT practitioners in applying evidence, their skills in accessing and interpreting it to provide personalised advice, and training requirements to optimise this, are important to understand.

1.5 Meeting the needs for nutrition advice for people affected by cancer

This section considers the need for safe, accurate, nutrition information for people affected by cancer and how they may obtain it. Firstly, evidence will show that people affected by cancer have unmet needs for appropriate advice within the UK, and, for comparison, in two other countries with different health systems. Current provision of advice is explored with regards to healthcare professions, and other sources of information used by people affected by cancer are discussed. Recent action in recognition of inadequacy of provision within the UK is described.

Cancer care within the UK is provided mostly through the National Health Service, which is funded from taxation, but with provision from cancer charities which may provide patient care in collaboration with the NHS, such as providing specialist nurses (Samson, 2016), or in cancer patient support centres separately from the NHS (Polley et al., 2016). Some aspects of provision for cancer care are planned centrally and an independent cancer taskforce was established in 2015 to deliver whole-person cancer care (Kumar, 2016). Within this framework, the need to support people living with and beyond cancer is acknowledged, and should include advice on diet and lifestyle to support recovery and improve survival (Kumar, 2016).

Studies from countries with various models of healthcare delivery, including the UK, have examined the need and provision for nutrition advice for people affected by cancer from a number of perspectives. For example, a qualitative study from the US, where healthcare provision includes insurance, self-pay and social provision (Mossialos et al., 2016) conducted interviews with 33 medical and nursing practitioners. Although some practitioners viewed the diagnosis of cancer as a 'teachable moment' when health messages are more effective, opportunities to give diet and lifestyle advice were sometimes considered unimportant by the practitioner (Coa et al., 2015). Participants noted that opportunities were often missed due to time constraints or perceived lack of benefit. This concurs with data from a survey of two thousand American adults which reported that only 30% cancer survivors reported receiving counselling on diet (Sabatino et al., 2007). In Korea,

where compulsory personal insurance funds universal healthcare (Lee, 2003), a survey of 830 lung cancer patients reported that dietary advice remained an unmet need for many (Yun et al., 2013). Within the UK, in an evaluation of 782 cancer patients' perspectives, using a self-rated measure of health concerns, accurate information on nutrition and diet emerged as one of their most important concerns (Polley et al., 2007). This is supported by data from three qualitative studies conducted in the UK with people affected by cancer. One study used interviews with nineteen participants to explore perspectives on diet after treatment for several different types of cancer (Beeken et al., 2016), and two studies interviewed men affected by prostate cancer, their partners and healthcare professionals involved in cancer care (Avery et al., 2014, Sutton et al., 2017). Themes emerging from all three studies suggested that diet was indeed important to people living with and beyond cancer, that they were open to, and wanted, dietary advice after their cancer diagnosis, but few received it.

Nutrition advice for people affected by cancer where it is available may be delivered within the NHS by nurses or dietitians (Selwood et al., 2010, Hopkinson et al., 2011, Murphy and Girot, 2013) and collaboration between nurses and dietitians or nutritionists has been proposed as an approach for delivering advice to cancer survivors (Murphy and Girot, 2013). There may be NT practitioners with longstanding experience of safely and effectively supporting people with cancer, and who may be working in collaboration with mainstream healthcare. However, until now, data on working with people affected by cancer has not been documented for the UK NT profession.

In the absence of advice from healthcare professionals, patients often seek information from the internet (Mattsson et al., 2017), which is unregulated and has information of variable quality and reliability (Warren et al., 2014, Kitchens et al., 2014). It is of concern that European and Japanese surveys suggest that most cancer patients seeking information on special diets, supplements and other complementary medicine rely on family members, friends, the internet and other communication media (Mattsson et al., 2017), rather than healthcare professionals. (Hyodo et al., 2005, Molassiotis et al., 2005). Appropriate delivery of safe, accurate nutrition information could

therefore meet an important need for people affected by cancer, which is poorly met by existing provision (Selwood et al., 2010, Hopkinson et al., 2011, Murphy and Girot, 2013, Fang and Heckman, 2016)..

Overall therefore, there is evidence from several countries from patient and practitioner perspectives, that accurate and appropriate nutrition is important for many people affected by cancer, but for some at least it remains an unmet need. Provision of nutrition advice for people affected by cancer within the NHS is recognised as variable, with inconsistent advice that may not reflect evidence (Selwood et al., 2010, Hopkinson et al., 2011, Murphy and Girot, 2013). Indeed in recognition of the unmet need for evidence-based nutrition information for people affected by cancer in the UK, the National institute of Health Research (NIHR) instituted a collaboration to identify areas for research and improvements in the delivery of appropriate nutrition information for cancer patients and survivors (National Institute for Health Research, 2015).

1.6 Safety concerns regarding the use of nutritional supplements by people affected by cancer

Having identified that people affected by cancer have unmet needs for appropriate nutrition advice, and that the relevant evidence base is complex and incomplete, this section explores safety considerations for cancer patients and the use of nutritional supplements during and after treatment. Specific examples of studies are discussed to highlight the sources of concern and areas of unresolved evidence.

There is widespread use of complementary and alternative medicine (CAM) by individuals affected by cancer including nutritional supplements (Frenkel et al., 2010). For example, one Scottish NHS out-patient breast clinic surveyed their breast cancer patients and survivors over a six-month period on CAM use (McLay et al., 2012). 360 women responded, of whom 250 reported current use of CAM or use within the last year. 50% of all those 'ever users' of CAM reported the use of nutritional supplements such as individual vitamins or combinations, or food compounds taken in addition to

diet. Patients do not always discuss the use of nutritional supplements or special diets with their oncology team (van Tonder et al., 2009) and concern has been expressed about the safety of such nutrition interventions by patients with cancer (Wedlake et al., 2010, McLay et al., 2012). For example, particular concern has been voiced about the safety of supplements with oestrogen-like properties, such as soya, for women affected by types of breast cancer that are stimulated by oestrogen (McLay et al., 2012). Furthermore, for patients receiving active cancer treatment, the potential for interactions between nutritional supplements and medication or radiotherapy is an important consideration which will be discussed here. Firstly, the use of some supplements including nutrients and botanical preparations may affect the rate at which some medicines are metabolised (McLay et al., 2012). This can apply even to foods and is exemplified by the interactions between grapefruit and many different drugs not confined to cancer care (Seden et al., 2010). Secondly, there is specific concern that the concomitant use of some antioxidant supplements such as vitamins A, C, and E with cytotoxic drugs or radiotherapy may reduce the effectiveness of treatment, by reducing the oxidative damage by which many cancer treatments work (Hong et al., 2015) even though dietary antioxidants play a role in cancer prevention (Gonzalez and Riboli, 2010). This is a complex area as different cancer treatments work by different mechanisms that may be open to interference by certain substances (Hong et al., 2015, McLay et al., 2012), but *in vitro* and *in vivo* data may be suggestive of interference (Nakayama et al., 2011, Jia and Liu, 2013) and some clinical trials conducted in this area reinforce this cause for concern. For example, a prospective randomised trial in 540 patients receiving radiotherapy for head and neck cancers (Meyer et al., 2008) demonstrated an association between poorer outcome amongst smokers given forms of vitamin A (beta-carotene) and vitamin E (alpha-tocopherol). Recurrence, cancer mortality and all-cause mortality were increased in supplemented smokers but not evident in non-smokers. This concurred with data that emerged from the ATBC and CARET lung cancer prevention studies (Fritz et al., 2011, Omenn, 2007) which reported higher rates of lung cancer in smokers supplemented with beta-carotene alone or in combination with vitamin E. Conversely, positive outcomes were reported in a larger

prospective cohort study of 4877 Chinese women followed for six months after diagnosis with breast cancer (Nechuta et al., 2011); women who supplemented with multivitamins and the antioxidants vitamin C and E had a lower rate of cancer recurrence (22% reduction) and mortality (18% reduction) compared with unsupplemented controls. This effect was regardless of whether supplementation was concurrent with chemotherapy, but the apparent benefit did not extend to those undergoing radiotherapy, which again question the use of antioxidant supplements during radiotherapy. However, the study was in women only, the rate of smoking in the trial participants was low, participants had a different type of cancer and the vitamins used included multivitamins as well as single and combined antioxidants. This suggests that study data on nutritional supplement usage may not be generalizable across different cancer types, populations and supplement combinations. Furthermore it reinforces the complexity of evidence on nutrition interventions and the potential risks of inappropriate supplement use by people affected by cancer.

Although some authors have proposed complete contraindication of antioxidant supplements during cancer treatment (Block et al., 2009), the Society for Integrative Oncology has developed specific clinical guidelines on the use of nutritional supplements and botanical products during cancer treatments (Deng et al., 2009, Frenkel et al., 2013) This recommends that cancer patients who choose to use supplements are referred to “*a trained professional*” for advice on their use, and that monitoring and clinical guidelines are adhered to. More recently, specific evidence-informed guidance for integrating nutrition interventions and other complementary therapies in lung cancer care has also been developed by the same group of integrative medicine clinicians and healthcare practitioners (Deng et al., 2013).

It has already been demonstrated in sections 1.3 and 1.4 that the evidence on diet and cancer is complex and incomplete, and evidence reviewed in this section highlights that there are questions about safety in the use of some nutritional supplements, particularly antioxidants during some cancer treatments. It could be argued that NT practitioners require specialist training

to work safely with people affected by cancer, particularly during active treatment. Moreover the potential for interactions between supplements and cancer treatments (Hong et al., 2015, McLay et al., 2012) underscores firstly the need for NT practitioner skills in accessing and critically appraising evidence. It also highlights the importance of communication between oncologists, their patients, and practitioners providing advice on nutritional supplements (Greenlee et al., 2014), which has not previously been explored from the perspective of nutritional therapists.

In summary, there are safety concerns surrounding the use of some nutritional interventions, particularly supplements, in people affected by cancer, but considerable complexity exists in the clinical situation for each patient. Evidence highlights the potential for interactions between drugs and nutritional supplements and even foods, but particularly for people affected by cancer, between antioxidants and radiotherapy, as well as the potential for some antioxidant vitamins to adversely affect outcomes in smokers. People affected by cancer may seek nutrition advice which may include advice on the use of nutritional supplements, and therefore to support best practice, there are compelling reasons to research current NT practitioner perspectives, including appropriate skills in the use of evidence and specialist training in working with people affected by cancer.

1.7 Specialist training for working in cancer care

Having established that skills and knowledge of nutrition practitioners have implications for the safety of cancer patients and survivors, this section considers the provision for specialist training for working with people affected by cancer, and identifies differences between provision for mainstream healthcare professionals and NT practitioners.

Specialist medical training and advanced practitioner status are well developed for mainstream professions, with formal frameworks for medicine (British Medical Association, 2017) and nursing (Royal College of Nursing Cancer and Breast Care Forum/UK Oncology Nursing Society, 2017). Post-qualification nursing courses in cancer and palliative care, for example, (Gail,

2008, Bucks New University, 2012) and post-graduate courses in oncology pharmacy practice (British Oncology Pharmacy Association, 2012) provide formal specialist training. Furthermore, a number of special interest groups exist to share knowledge and best practice in cancer nursing (UK Oncology Nursing Society, 2012, The National Forum of Gynaecological Oncology Nurses, 2012) and pharmacy (British Oncology Pharmacy Association, 2012). Continuing professional development (CPD) courses for dietitians and specialist radiography training are available, to equip the practitioner for specialist cancer work. Post-qualification training for dietitians leading to the Diploma in Advanced Dietetic Practice is available at a number of institutions, and a special interest group of oncology dietitians operates within the British Dietetic Association (British Dietetic Association, 2017).

The NOS and Core Curriculum for NT include training in accessing, critically appraising and applying evidence in practice. They also include training in the safe use of nutritional supplements (Complementary & Natural Healthcare Council, 2017, Skills for Health, 2010c), but detailed training in the support of people affected by cancer is not compulsory for course accreditation. Furthermore course accreditation is voluntary (Nutritional Therapy Education Commission, 2017). This means that there may be varying levels of knowledge and skill amongst NT practitioners on how to provide appropriate advice to patients with cancer, or cancer survivors.

Until now, there was no documentation of specialist training provision for NT practitioners who work with people affected by cancer, nor of practitioners' perspectives on their training needs.

1.8 Inter-professional relationships and boundaries in healthcare

In this section, some aspects of dynamics between healthcare professions are considered, with reference to specific studies that have informed this doctoral research. This serves to contextualise the exploration of inter-professional relationships that may have bearing on the work of NT practitioners working with people affected by cancer. As identified in section 1.2.1, there are tensions between the three nutrition professional groups and

specific criticism from within the two long-established professions, dietetics and nutritionist, that the NT profession is unregulated and not evidence-based. This may be interpreted in part as a response to contested professional boundaries (King et al., 2015, Nancarrow and Borthwick, 2005). Research with other healthcare professions has explored the perspective of practitioners on inter-professional dynamics and changing professional roles; for example neonatal nurses' perspectives on their training for advanced practitioner roles has been studied using focus groups, interviews and a survey of five cohorts of graduates from a training programme (Nicolson et al., 2005). Concerns with professional role recognition and relationships with other nurses and with doctors were identified. In sports science, where physiotherapists work independently and collaborate with physicians, practitioners' perspectives on power-shifting and organisational change were explored (Malcolm and Scott, 2011). Questionnaires and semi-structured interviews with 14 doctors and 14 physiotherapists identified how conflict and cooperation occur between the two groups in delivering specialised care, particularly in elite sports. Each profession appeared to protect their clinical domain, but boundaries were also shifting as doctors conceded areas of practice and status. Nurse practitioners also challenge medical primacy by assuming advanced practice roles; job satisfaction amongst 17 nurse-practitioners was explored using a paper questionnaire, whilst their collaborating physicians were also surveyed separately. Despite a high rating for professional autonomy amongst the nurse practitioners, they revealed low levels of overall job satisfaction, even though their physician colleagues rated their contribution highly (Pasaron, 2013). Areas of discontent were in professional and monetary recognition, ability to exert influence, administrative support and inter-professional relationships. Relationships between mainstream healthcare and CAM practitioners have been explored from a number of perspectives, and particularly within cancer care, and some putative barriers to dialogue and engagement have been identified (Schiff et al., 2011, Ben-Arye et al., 2007, Ben-Arye et al., 2013).

In summary, a number of studies of the relationships between professions, where roles are changing and professional boundaries being challenged have provided evidence that has informed this research.

1.9 Studies of complementary medicine practitioners perspectives

This section outlines relevant literature on researching complementary medicine practitioner perspectives in healthcare that have informed the design of this study. The literature reviewed here identified specific aspects of study design particularly sampling from CAM professions with some similarities to the NT profession. Methods used to research attitudes amongst CAM professions to mainstream healthcare are also reviewed.

Practitioner perspectives on training, the role and use of research, professional development and identity, and inter-professional dynamics and communication, have been documented in several other healthcare contexts. Specific challenges encountered in research with other CAM professions arise in the UK from the lack of compulsory regulation, and from working arrangements that are generally separate from NHS provision. Firstly, postal and on-line surveys of Australian naturopaths and herbalists collected data on qualifications, duration of clinical experience, attitudes to regulation and evidence, and information sources used (Bensoussan et al., 2004b, Braun et al., 2013b, Novak and Chapman, 2001a, Molassiotis, 2005). These three Australian surveys used different recruitment methods but none had a clear measure of their target population, due to lack of formal registers and overlaps between membership lists of several practitioner associations, so that there was a potential for duplication of participants. This underscores the need for a tightly defined sample population with specific professional standards, such as identified for a national registration scheme, and identifiable routes to the population for survey recruitment.

A number of studies providing examples of different research methods used with other CAM professions have informed the design of this study; practitioner perspectives were explored with massage and bodywork practitioners, discussing the role of research, training, practice settings and

use of treatment techniques (Porcino et al., 2011). 791 predominantly female practitioners participated in the survey and 19 were interviewed; themes of individualization and evolution of treatment, and training complexity emerged. Notably, a theme emerged of dissonance between standardised treatment protocols used in research and individualized treatments used in practice, questioning the relevance of research. A larger study of 3148 bodywork practitioners in the US used an on-line survey to research training and information sources used, and practitioners' views and personal use of CAM and mainstream medicine. Preference for CAM therapies and ambivalence toward mainstream medicine emerged, although most participants used mainstream healthcare services personally and referred clients for them (Footracer et al., 2012). Finally, a multidisciplinary team of mainstream healthcare and social researchers used personal interviews of 32 CAM practitioners from 20 different professions, to explore their perspectives on CAM and mainstream healthcare (Barrett et al., 2004). Respect for, and a desire for integration with, mainstream healthcare emerged as a major theme, and the perceived attitudes and beliefs of mainstream professionals towards CAM emerged as the greatest barriers to cooperation and integration. As identified in section 1.2, one of the professional issues that this research seeks to address for the NT profession, is the question of relationships and communication with mainstream healthcare professions. Until now, NT practitioner perspectives on this issue have not been explored.

1.10 Rationale for this research

This literature review identifies that the NT profession is poorly documented overall and that practitioner perspectives on working with people affected by cancer have not previously been explored. As discussed in section 1.2.1, the NT profession is one of three identifiable nutrition professions in the UK. There are areas of commonality with the other two professional groups, dietitians and nutritionists, and professional tension arises from contested professional boundaries with both professions. Whereas dietitians work within cancer care teams, NT practitioners work independently and outside of

the National Health Service, which may have implications for professional isolation and communication with other healthcare professions. Although there is practitioner registration and accreditation of training to the National Occupational Standards for the NT profession, both are voluntary, and there is no formal framework for post-qualification training. NT practitioners may be working with people affected by cancer to provide nutrition information, but until now there is scant documentation of the extent and context of NT practice in this clinical area, or of NT practitioners' training and experience, or their perspectives on this work. As demonstrated in sections 1.3 and 1.4, the evidence base that can inform the advice for people affected by cancer is complex, and in several areas incomplete. The perspectives of NT practitioners on accessing, interpreting and using evidence in practice has not previously been documented. The provision of appropriate nutrition advice to people affected by cancer is acknowledged to be inadequate in the UK (National Institute for Health Research, 2015), and as discussed in section 1.6, there are safety concerns about the use of some nutrition interventions by people affected by cancer. Research in this area is therefore of considerable importance and urgently needed from a patient care perspective.

Practitioner perspectives within mainstream and complementary medicine have been explored from a number of dimensions, using quantitative and qualitative methods in various study designs. This literature review has identified research that has explored training and professional development, use of research evidence, and inter-professional relationships for a number of other healthcare professions. These have informed the development of the research question, and in time may inform professional practice and development for the NT profession.

Until now, therefore, for the nutritional therapy profession, practitioner perspectives on working with people affected by cancer have not been systematically explored. This study provides insight into an important area of healthcare practice.

1.11 Research aims and objectives

The aim of this research project is to explore nutritional therapy practitioner perspectives on working with people affected by cancer.

The objectives are:

1. To recruit two groups of registered nutritional therapists who actively work in the UK: i) practitioners with clients affected by cancer, ii) those who do not work with people affected by cancer, but who may wish to do so.
2. To describe and compare the professional characteristics of the two identified groups.
3. To explore cancer practitioners' perspectives on working with cancer clients and their needs for future professional development in this area, through collecting and critically analysing qualitative questionnaire data and by using focus groups and one-to-one interviews.
4. To explore non-cancer practitioner's reasons for not undertaking cancer-related work and the resources they perceive could enable them to become cancer practitioners, using these qualitative methods.
5. To use these data to inform and support the professional development requirements of nutritional therapists in the area of cancer practice.

Chapter 2. Study design and methodological considerations

2.1 Introduction

In this chapter, theoretical considerations and underpinning for the choice of research design are discussed. As defined in the section 1.11, the research aims and objectives encompassed the collection of professional characteristics data from two cohorts of practitioners, followed by exploration of their perspectives on working with people affected by cancer. Therefore the study collected both quantitative and qualitative data. This chapter therefore explores the philosophical considerations of combining research methods that are based on apparently contradictory ontological and epistemological foundations, in a mixed methods study design. Some of the theoretical tensions emerging within the mixed methods paradigm are discussed. Pragmatism is explored as the philosophical perspective underpinning mixed methods research that this doctoral researcher aligns with. Methods that were potential candidates for collecting and then analysing qualitative data from practitioners are then discussed, with three factors influencing the choice made: firstly the intended use of the research outputs, as identified in section 1.11, to support professional development for NT practitioners, that is, to influence policy. The second consideration in the choice of methods for data collection was the literature on dynamics of relationship between research participants and a researcher-practitioner from the same profession. Thirdly, the research experience of the researcher also influenced the data collection method chosen.

Finally, this chapter considers the reflexive position of the researcher, whose researcher's perspectives are informed and influenced by professional positions as an NT practitioner, in regulatory roles and past professional work in mainstream life sciences.

2.2 Mixed methods rationale and philosophical framework

This section discusses the justification for combining quantitative and qualitative research methods (Schwandt, 2001) in a mixed methods study design, addressing questions of research rigour, and considering pragmatism as an underpinning paradigm. Mixed methods study designs are increasingly used in health research to provide broader perspectives on research questions (Wisdom et al., 2012), including in complementary and alternative medicine (CAM) (Bishop and Holmes, 2013). Having evolved from both quantitative and qualitative social research disciplines, mixed methods research may be aligned with a number of philosophical perspectives, such as critical realism (McEvoy and Richards, 2006), and, as proposed in this study, the pragmatic paradigm. Pragmatism proposes that the world as experienced is multi-layered, with objective and subjective facets, with both order and uncertainty, and that the consequences of ideas determine their meaning (Johnson and Onwuegbuzie, 2004, Morgan, 2007). In the pragmatic approach, consideration of the outcome and consequences of research determine the methods used, such that measurement of subjective phenomena may use 'subjective' qualitative means, and objective phenomena may be measured quantitatively (Feilzer, 2010). Although seemingly superficial and simplistic, and sometimes dismissed as simply "what works" (Hannes and Lockwood, 2011), pragmatism acknowledges that the lived experience has both abstract and concrete elements, each deserving different means of enquiry and perhaps philosophical standpoints. Pragmatism as a research paradigm may claim lineage from the philosophy of classical pragmatism (Morgan, 2014), as expounded by James and others (Hickman, 2004), who argued strongly against dualism and polarisation of ideas and theories, (Colapietro, 2004), and particularly Dewey (Midtgarden, 2012), who advocated for the process of inquiry as central to resolving social questions (Hathcoat and Meixner, 2015).

The legitimacy of pragmatism and of mixing methods, however, is challenged by the 'incompatibility thesis' (Morgan, 2007, Creswell, 2008), proposed by purists in both quantitative and qualitative disciplines in social research. Their

position is that philosophical and methodological incompatibility between quantitative and qualitative approaches prevents meaningful integration or combination of methodologies. However, the 'conditional incompatibility' thesis (Hathcoat and Meixner, 2015) proposes there will be situations within mixed methods studies where epistemological conflict arises in the proposed mixing of methods, and that researchers must address those conditions. This has some commonality with the 'anti-conflationist' perspective (McEvoy and Richards, 2006), which suggests that mixing quantitative and qualitative methods is possible if there is a common position on ontology and epistemology, which should be considered apart from (not conflated with) methodology. Conversely, the 'dialectical pluralist' position (Johnson, 2017) argues that dialogue and interplay between two paradigms being 'mixed' should actively occur to ensure integrity. Finally, the transformative paradigm in social research also embraces mixed methods, justifying mixing methods by the imperative to enact social justice (Mertens et al., 2016).

The position of this researcher is that mixing quantitative and qualitative methods, situated within the pragmatic paradigm, has philosophical credibility if potential conflicts of methodologies are examined and resolved, as framed by the conditional incompatibility thesis. These considerations are discussed in detail in the next section.

2.2.1 Questions of rigour, 'validity' or credibility and legitimation in mixed methods research

A systematic review of 80 mixed methods studies in CAM published within one year (2012) reported that potential epistemological and philosophical conflicts in mixing methodologies were rarely addressed (Bishop and Holmes, 2013). The authors reported that incongruities remained unaddressed in all 80 studies, and called for greater rigour in using mixed methods in CAM. They noted particularly the need to acknowledge the impact of the researcher in collecting qualitative data within mixed methods studies. It could be argued that this should be fundamental in all qualitative data collection in CAM research, regardless of study design.

As the use of mixed methods designs expanded and developed, a number of authors explored the basis for assessing 'quality' or 'rigour' (Brannen, 2005, Greene, 2008, Onwuegbuzie et al., 2011, Creswell et al., 2011). Brannen (2005) proposed that the criteria used to judge the 'quality' of mixed research could be determined by the dominant paradigm in the programme, for example research in which quantitative research predominates could be judged by the criteria of reliability, reproducibility and generalisability; criteria that would not be appropriate for predominantly qualitative research. Greene (2008) by contrast, explored a different approach and defined four domains to be addressed, to ensure rigour in the development of mixed methods programmes, regardless of the predominant paradigm. These domains are: philosophical assumptions and stances, inquiry logistics, guidelines for research practice, and socio-political commitments. Building on this to address further the concept of research credibility or 'validity', Onwuegbuzie (2011) mapped nine areas of 'legitimation' across Greene's four domains. Legitimation was proposed as a term to indicate credibility in qualitative and mixed methods research (Onwuegbuzie and Johnson, 2006) rather than 'validation', since 'validity' is a concept rejected by some post-modernists as loaded with meanings of rules, logic and objectivity, and hence more relevant to a purely quantitative positivist research perspective (Schwandt, 2001). Legitimation addresses questions such as theoretical paradigmatic mixing and compatibility of the two methodological strands, but also practical issues such as weakness minimisation within the overall design, wherein the strength of the qualitative approach can support a weak facet of the quantitative method and vice versa (Onwuegbuzie et al., 2011).

Greene and Onwuegbuzie's aforementioned schemes provide a framework for firstly demonstrating credibility, but also for scrutinising congruity and compatibility between the paradigms and methods being mixed, which is used here to address the conditional incompatibility thesis. Therefore, in considering this study design for potential paradigmatic incongruence, each of Greene's four domains is herewith addressed with reference to Onwuegbuzie's nine components of 'legitimation':

1. Philosophical Assumptions and Stances

Legitimation in this domain requires firstly that external (etic) and internal (emic) views of the phenomenon are both valued (inside-outside legitimation). These may be represented respectively by the practitioner characteristics data and the practitioner perspectives, which can be seen to be separate and yet connected. For example, the number of practitioners with higher degrees could be considered an unambiguous 'fact' that can be reliably ascertained from quantitation, whereas the habits of practitioners in accessing the published evidence base, whilst perhaps influenced by their level of qualification, is a question best explored by qualitative means, to research the lived experience of practitioners, which is a subjective phenomenon.

The second point of legitimation mapped in this domain requires that both quantitative and qualitative research paradigms are accommodated (paradigmatic mixing legitimation). Since this study design is squarely based in the Pragmatic paradigm, both paradigms are accommodated and the methodology is determined by the consequences (desired outputs) of the methods chosen. The design draws on complementary aspects of the disciplines of quantitative and qualitative research, with the first phase enabling purposive sampling for the second phase. This also aligns with the third point of legitimation, which requires appropriate switching between the two paradigms (commensurability legitimation).

2. Inquiry logistics (methodology)

Addressing Greene's second domain of rigour, five components of Onwuegbuzie's legitimation framework are considered: weakness minimisation, sequence, consideration of data conversion and of sample integration, and accommodation of multiple validities. With regard to sequence, the programme reported in this thesis used two sequential phases, each could be conducted completely independently; however by correct sequential timing, Phase 1 facilitated purposive sampling for Phase 2 and informed interview design. This also demonstrates weakness minimisation in that potential sampling weakness for phase 2 is

countered by including recruitment for phase 2 in the phase 1 survey. Legitimation in data conversion has been considered; data collected from open ended questions in the survey questionnaire led to preliminary themes that were enumerated. However, sample integration was not undertaken, that is the survey responses provided by interview participants were not identified, so that their survey responses would remain anonymous and separate from interview data. In designing the study, opportunities for data corroboration, contradiction or elaboration between phases were incorporated by question design and sequence, accommodating multiple validities. Data analysis led to comparison between the two phases of some data sets.

3. Guidelines for research practice

In considering Greene's third domain of rigour, that of adherence to research guidelines, four of Onwuegbuzie's legitimation components are again mapped here: sequence, conversion, sample integration, and impact of multiple validities. Overall, this doctoral study followed the Medical Research Council research guidelines (MRC, 2012) and university ethics guidelines. The study design also is framed by the US National Institutes of Health (NIH) practice guidelines on mixed methods research (Creswell et al., 2011), which considers questions of sequence, conversion, and sample integration and describes consideration of rigour in the application of each component of mixed methods designs.

4. Socio-political commitment

Considering the fourth of Greene's domain, aligned with this is Onwuegbuzie's question of political 'legitimation' of the research design. A number of aspects of study design were considered from a socio-political perspective. Firstly, this study explores practitioner perspectives which may have potential implications for patient care and professional practice, and hence social currency. Built into the study design are considerations of collecting data of relevance for patient safety (for example training standards and use of evidence) and of relationships with other healthcare professions. A further socio-political perspective to be

considered is that of healthcare regulation, which was considered from two aspects, firstly the outcomes may have relevance for the regulatory framework for the profession studied. For example it could provide data that has relevance for the current voluntary regulatory status of the profession. Additionally, this doctoral researcher has been involved in regulation since establishment of the regulatory process for NT profession, and the possible impact of this on research participants was considered in the design of the programme. This was particularly in considering power relationships and social desirability effects (see further discussion below in 2.4). Planning of research output and dissemination of research findings also addressed socio-political considerations, in that the data will be used to influence a major professional association representing practitioners. There are no perceived explicitly political implications inherent in the study design.

Therefore, rigour and credibility of the study design reported in this thesis have been systematically considered against a formal framework.

Finally, it is worth commenting that the increasing use of mixed methods led to the establishment of an international task force to explore future directions of the field and research rigour (Mertens et al., 2016). This moved the debate beyond questions of 'validity' or credibility of combining methods.

'Triangulation' between study phases and datasets, and between researchers has been advocated as a core element of mixed methods research (Howe, 2012) and data integration also proposed as essential to synthesizing new perspectives on social problems (Fielding, 2012). However, in this doctoral study, sample and data integration were avoided, to preserve anonymity of the survey, but comparison between phases has taken place.

2.2.2 Mixed Methods Research typologies

The use of typologies has been proposed for mixed methods programmes, to describe the order, predominance and epistemological approaches of the combined design (Leech and Onwuegbuzie, 2009, Creswell, 2008, Johnson and Onwuegbuzie, 2004, Guest, 2013, Mason, 2006). Typologies may be

considered useful for communication about research, by providing a common language and structure (Guest, 2013). The study reported in this thesis was completed in two phases; firstly a survey to collect predominantly quantitative data, which informed the interview phase which collected qualitative data. The sequence and methods chosen were designed to firstly map the landscape of a previously undocumented professional practice, and then to explore in detail practitioners perspectives of that practice. The qualitative data is given more weight since the overarching aim is to explore practitioner perspectives, which is best approached by qualitative means. This programme therefore followed an explanatory design according to Creswell and Plano-Clark's schema (Creswell, 2008), or could also be described as a partially mixed sequential dominant status design, typology P4, according to Leech & Onwuegbuzie (2009), with qualitative data being considered predominant. Mason's (2006) approach is to consider typology based on research design logic, and this study would be considered to be based on parallel logic, as the study addressed a separate question with each phase (Mason, 2006). However, it has been argued (Guest, 2013) that most typologies do not adequately describe mixed methods studies and proposes instead that researchers may place less importance on formal classification schemes and instead describe timing and the purpose of data integration. It could be argued that although this would convey some important elements of mixed methods designs, it would not, for example, emphasise the relative weight given to each phase, as many typologies do. However some typologies could be said to have shortcomings in attempting to be at the same time descriptive and precise. For example in Creswell and Plano-Clark's description of explanatory design, emphasis on quantitative data is presumed (Creswell, 2008), but in the study reported in this thesis, the qualitative data is given greater emphasis in the analysis of practitioner perspectives. Therefore in using typologies to describe this study, schemata proposed by Mason (2006) and Leech & Onwuegbuzie (2009) would appear appropriate to communicate the essence of the design.

2.3 Surveys within a mixed methods design.

This section reflects on data that may be collected via survey questionnaires. In addition to collecting numerical data, such as demographics, surveys are also used to collect data on attitudes, including amongst healthcare professionals and patients (McColl et al., 2002). Although 'attitudes' may be considered qualitative phenomena, measurement of them in a survey would be considered quantitation (Fielding et al., 2013), even though collecting data on healthcare attitudes using open-ended survey questions is occasionally reported as 'qualitative research' (Toeima and Nieto, 2011, Bos-den Braber et al., 2015). However, it could be argued that qualitative data can only be collected in person, that the physical presence or engagement of the researcher imparts a dimension to face-to-face interviews that a survey questionnaire cannot (Minichiello et al., 2008, Seymour, 2001), with the implicit value of the researcher as data collection tool inherent in the qualitative view. Conversely, an anonymous survey participant may feel less constrained in their replies, and the data collection process less value-laden, than a personal interview (Seymour, 2001). In this study, the open-ended questions in the survey serve to collect data to inform the more in depth interview phase.

2.4 Qualitative data collection methods

In this section, methods for collecting qualitative data on practitioner perspectives are first considered. The chosen method of interviews is discussed, particularly the considerations of interviewing professional peers. The impact of conducting interviews in person or at a distance are then considered.

Social phenomena can be explored using a variety of methodologies which may be underpinned by different epistemological positions. Ethnographic techniques (Jones and Smith, 2017, Reeves et al., 2008) aim to collect data on cultures, social groups and interactions, traditionally by direct observation, and sometimes supplemented by interviews. As a foundational qualitative

method used in social research, developed particularly in anthropology (Reeves et al., 2008), it can require the long-term participation of the researcher, and in some cases immersion in the social group (Reeves et al., 2008). It may therefore be time-intensive, generate a large body of data, and involve a considerable depth of fieldwork. Focussed ethnographic studies limit their observations to specific phenomena (Bikker et al., 2017) and have been used in healthcare research to explore aspects of nursing practice (Jangland et al., 2017) and smoking cessation counselling in community pharmacy, for example (Rivas et al., 2017). Some ethnographic approaches do involve the researcher being fully integrated into the observed group (Jones and Smith, 2017), and as a practitioner-researcher, this doctoral researcher could already be considered an 'insider'. This methodology was therefore feasible, but firstly is not specifically purposed to guide or inform policy, it is more often used to understand a social phenomenon or culture (Jones and Smith, 2017). Secondly, the doctoral researcher's position in professional regulation may have impacted adversely on the trust relationship required to inhabit the social group being studied. Furthermore, from the perspective of this researcher, there was a risk of insufficient transparency, detachment and trustworthiness of data collected by ethnographic methodology. Finally, with specific ethical concerns about observing practitioners in their daily practice, the technique was therefore not considered further.

Diaries, either unsolicited and unstructured, or prompted and structured, may be used for collection of qualitative data from healthcare practitioners and patients (Kenneth Jones, 2000), in studies of participants over time. Diary material in such longitudinal qualitative studies may be supported by other data such as interviews, for example in a study of gossip and emotion with 96 nurses in a variety of healthcare settings (Waddington and Fletcher, 2005), which used structured diaries. Interviews also supplemented data from audio diaries from 20 trainee doctors' recruited to a study of their perspectives of their transition from trainee to doctor, over a 9-month period (Gordon et al., 2017). Very short duration studies may also use diaries, for example a cohort of 47 parents of Dutch children with disabilities recorded

their experiences over 7 days (Piskur et al., 2017). Mixed methods study designs may also combine diaries with the collection of quantitative data, for example in a study of knee pain, patient diaries collected qualitative data to complement quantitative data from pain and disability scores (Jinks et al., 2007). The use of diaries may have been useful in this doctoral study of practitioner perspectives, as part of the qualitative phase. However, the lack of experience of the researcher in their use, and again the power dynamic between researcher and participant, are considerations that may incur disadvantages in their use in this specific doctoral study. Further research with the practitioner cohort in this doctoral study may consider using diaries to research specific aspects of professional development, for example.

Interviews are widely used in qualitative research (Lambert and Loiselle, 2008) and may be combined, as discussed above, with other qualitative techniques such as observation in ethnographic studies (Bikker et al., 2017) or diaries in longitudinal studies (Gordon et al., 2017). Interviews may take place with individuals or groups. The group method of focus groups, which may be used to explore specific issues, can provide rich data from the group dynamic and interactions (Lambert and Loiselle, 2008, Carey and Smith, 1994, McLafferty, 2004). Focus groups may be useful when there is a perceived power difference between researcher and participants (Morgan and Kreuger, 1993). They may be useful to augment data collected by individual interview, for example, practitioner perspectives on training and personal and professional development were studied with neonatal nurses preparing for advanced practitioner roles, using focus groups, interviews and a survey (Nicolson et al., 2005), which also illustrates the complementary use of survey and interview in researching professional development. Compared with individual interviews, focus groups may reveal more information on the social realities of a group, enabling participants to explore and develop their ideas during the process of discussion (McLafferty, 2004). Other group interview methods include consensus panels (Coreil, 1994) which include participants with a specific common interest.

In a comparison of individual interviews and focus groups, exploring patient perspectives on living with rheumatoid arthritis, data saturation was reached

sooner with focus groups (Coenen et al., 2012). Other authors have argued that focus group participants revealed more than those interviewed individually (Kitzinger, 1995) since the group environment may encourage those who are reluctant speak. It has also been argued that the type of data collected by the two techniques is different (Ezzy, 2001) and that the composition and structure of focus groups may impact on the data collected. Although these arguments in favour of focus groups for exploring participants' views may appear persuasive, it has also been argued (Coenen et al., 2012) that individual interviews may be better for exploring sensitive subjects and may require less resources and time to organise and administer. Furthermore, in his analysis of apparent interpretative bias in qualitative healthcare research, Ezzy (2001) argues that some focus groups may coalesce around negative views, and that participants may find that their views are suppressed or modified during the focus group process. Since the topic of this research is a previously unexplored aspect of healthcare practice, individual practitioner perspectives are of interest. Therefore a combination was used of individual interviews augmented by one group interview that explored one specific theme emerging from the survey data. A single issue emerging from the survey was explored in a group discussion with a committee of practitioners with a specific interest in that issue. A committee of a professional association served as a consensus panel (Coreil, 1994) to discuss the use of practice guidelines.

Individual interviews may take place synchronously, in person or via telephone or other communication media, or asynchronously using media such as e-mail or other form of message services (Opdenakker, 2006). Interview format may be tightly structured and standardised, with a script that is used by the researcher for all participants, or by contrast may have no structure and be entirely led by the participant, such as used in ethnographic studies (Dicicco-Bloom and Crabtree, 2006). Semi-structured interviews generally use open-ended questions by the researcher to guide the interview participant through a framework of topics for discussion, which can be flexible to allow exploration of specific areas of interest to the participant (Dicicco-Bloom and Crabtree, 2006). Semi-structured individual interviews

were chosen for use in this study to enable the preliminary themes emerging from the phase 1 survey to be used as topics for discussion in the interview. As a technique they are widely used in qualitative healthcare research with patients/service users and with practitioners, and specific considerations of their use in research with professional colleagues and peers has been explored.

Interviewing peers and colleagues in professional research, places the interviewer in a position of 'insider' within the profession. An 'insider' conducting research, however, may carry advantages, such as intimate knowledge of vocabulary, practices or structures, (Gair, 2012, Ritchie et al., 2009). The researcher may exploit their "insider/outsider" position within the researched domain, by using their understanding of language, symbols and common purpose, enabling more informed questioning or establishing rapport (Burns et al., 2012, Doykos et al., 2014). However, this may have disadvantages, notably a bias of perspective, where a culturally-entrenched stance may become a lens through which data is viewed. A further layer of complexity may arise from perceived power differentials between interviewee and interviewer, which are complex (Bravo-Moreno, 2003, Ben-Ari and Enosh, 2013, Karnieli-Miller et al., 2009). For example, in research with General Practitioners (Chew-Graham et al., 2002), participants were reported to have responded differently to an interviewer from their own profession who was perceived as an expert or authority, compared with a researcher from outside the profession. The authors noted that participants gave more detailed responses when interviewed by a GP-researcher, but some responses reflected a perception of the GP-researcher as judging participants' practices. This perceived power relationship was a consideration in this doctoral study, since the researcher holds a professional regulatory role which may be known to interview participants. Close attention to this dynamic, and to the potential for social desirability effect was considered. Furthermore, attention was paid to the perceived institutional positioning of the interviewer in the construction and delivery of questions, and even verbal emphasis, as this may influence the data collected in an interview (Tracy and Robles, 2010).

A further element of influence may emerge from the location of interviews (Gagnon et al., 2015), since interviews in person may be influenced by whether the interview takes place on the territory of the interviewee or the researcher, impacting on perceived dominance, although even the 'micro-geography' of a neutral location (such as social setting) may impact on the interview (Elwood and Martin, 2000). For example, research with nurses who were also carers of sick family members reported that interviews conducted in the nurses' workplace, often whilst they were in uniform, revealed less of the personal perspectives of the interviewee, and produced shorter more jargonised responses, similar to a clinical 'handover' (Quinney et al., 2016). In contrast, interviews at participants' homes provided a richer narrative of their personal experience, with less clinical detail, and the interviewees appeared more relaxed and in control.

Interviewing by telephone, chosen for this study, could be considered to remove the location element of the power dynamic and may allow the interviewee to feel more relaxed (Novick, 2008). It may also be valuable for exploring sensitive topics (such as the emotional aspects of working with people affected by cancer) and may limit distress to interview participants exploring difficult topics, such as healthcare practitioner stress (Mealer and Jones, 2014). Conversely, the ethical dimension of opening a discussion of such potentially distressing topics with a participant at a distance also bears consideration (Dicicco-Bloom and Crabtree, 2006). Establishing rapport between researcher and interviewee may be more difficult by telephone than in person (Novick, 2008), although removing a visual dimension to the interview may enable the two parties to focus more on the verbal exchange (Smith, 2005). Comparative studies of telephone versus face-to-face interviews suggest that although telephone interview participants may speak for a shorter duration (Irvine, 2011), the absence of non-verbal cues may lead to better probing by the interviewer, eliciting more detailed responses (Cachia and Millward, 2011). Guidance for conducting research interviews to optimise the collection of qualitative data (Musselwhite et al., 2007) suggests practical measures such as ensuring the interview is not hurried, that the aims of the interview are reviewed at the start, and using generic questions

to open the dialogue. Lower costs of telephone interviewing and rapid access to all geographically located participants (Novick, 2008) were also considered advantageous in the study reported in this thesis.

2.5 Analysis of text data generated within the survey

In this section, the analysis of data generated by open ended questions in survey questionnaires is considered. Even if analysed using qualitative data analysis tools, the data is generally considered quantitative (Fielding et al., 2013). Firstly it is collected without a record of the social context in which the questionnaire was completed. Secondly, content analysis of the text, and then assigning data to categories, could be said to remove further context from the data, such as the responses to other questions from the participant. Furthermore, content analysis, described as being at an intersection between quantitative and qualitative methods, accesses the manifest content of text data, but is less suited to analysing latent content (Kondracki et al., 2002). Therefore it produces a superficial representation of the survey respondents' perspectives, but by counting categories represented in the data it can produce patterns of responses (Seale and Silverman, 1997), and indicate trends in preliminary themes from the survey sample. For this research, therefore, text data collected by the survey provided preliminary themes to inform topics for deeper exploration in Phase 2.

2.6 Qualitative data analysis choice of methods

In this section, potential methods for qualitative data analysis are considered, including grounded theory, narrative analysis, and two different approaches to thematic analysis. The analytic process used in this study has been informed by the literature on mixed methods research in healthcare and the social context of the research question. As identified in the research question in section 1.11, this research was conducted to inform policy on professional development, therefore the methodological framework of the study was informed by the intended application of the research outputs. It was influenced by the researcher's reflexive position and philosophical alignment

with Pragmatism and took account of the experience of the researcher in analysing qualitative data.

Considering first the use of Grounded Theory; being entirely inductive in approaching data without *a priori* themes or hypotheses (Glaser and Strauss, 1967). A number of examples illustrate its strengths in identifying themes in exploratory research, for example for data from focus groups and individual interviews on information-seeking behaviour in cancer patients, (Lambert and Loiselle, 2008). It was also used in research in practitioner perspectives in CAM to explore themes in the use of traditional Chinese medicine in cancer care (McPherson et al., 2016) and to explore concepts of 'being accepted' by mainstream healthcare (Wiese and Oster, 2010). However, in the study design reported in this doctoral thesis, the use of Grounded Theory was discounted partly based on the researcher's lack of experience in its use, but foremost as the research topic was intended to lead to policy development in specific professional areas, which was better suited to other methods that had a deductive component (Ritchie and Lewis, 2003).

Narrative analysis (Polkinghorne, 1995) may be considered to be a research paradigm as well as a specific analytical technique which may be used to approach interview data. Narratives from participants are analysed to construct stories that may represent the participants' perspective, but also the meaning that participants attach to their story, and why they have narrated the events or story that emerged in the interview (Wang and Geale, 2015). Narrative analysis is situated within the social constructionist paradigm, it is less concerned with the 'facts' of a narrative, such as specific events or views that the participant may have discussed (Wang and Geale, 2015). Instead it is more concerned with the story as part of the identity that the participant projects in the social world; for example physiotherapists' professional identities have been explored using narrative analysis (Hammond et al., 2016). The patient experience may also be explored using narrative analysis (Onocko Campos and Furtado, 2008, Haidet et al., 2006). However, as an analytical approach for interview data it was considered to be less useful for this professional doctorate study, which has specific

objectives to understand participants' perspectives with the objectives of informing professional development.

In contrast to the purely inductive process of Grounded Theory, deductive methods of data were considered for analysis of qualitative data. Themes emerging from data can be coded, organised and analysed using thematic analysis (Braun and Clarke, 2006), which can be used as a tool within different methodological frameworks, including Grounded Theory. Braun and Clarke (2006) however, argue that it can be considered a methodology in its own right. Themes can be organised for example in Thematic Networks (Attride-Stirling, 2001), to illustrate relationships between data at Basic, Organizing and Global thematic levels. However, this methodology could be criticised for superficiality and for disconnecting data fragments from the original, thereby reducing its contextual relevance (Attride-Stirling, 2001). Framework Analysis, developed particularly for applied policy research, endows transparency in the researcher's interpretation of the data, and a clear audit trail of the analytical process (Ritchie and Lewis, 2003), and for these reasons was used for this study. As an analytical tool, it is flexible in being independent of the epistemological root of the study (Gale et al., 2013). A number of examples illustrating its use in healthcare research were considered in selecting it for the study reported here, which demonstrate its flexibility. For example in a doctoral study with parents of children with hydrocephalus, (Smith and Firth, 2011), it was used to analyse face-to-face interview data. It was used to analyse telephone interview data with service users of mental health services (Jeffery et al., 2013), and to analyse concepts emerging from 60 studies in an integrative review of patient participation in healthcare (Thórarinsdóttir and Kristjánsson, 2014). Particularly as Framework Analysis is considered suitable for strategic research, it was deemed suitable for the professional doctorate study reported in this thesis. Clearly, themes do not emerge spontaneously from qualitative data, they are identified within the data and therefore influenced by the researcher. In the study reported in this thesis, the analytical process used for interview data used predominantly deductive coding structured around the interview topics, with a degree of inductive coding deriving sub-

themes from the transcripts. This hybrid approach is accommodated within the Framework methods (Gale et al., 2013) and examples are documented of use in other doctoral studies (Gale et al., 2013, Smith and Firth, 2011)

2.7 The practitioner-researcher “insider-outsider” identity in social research

In this final section, the methodological considerations of using and analysing reflection in research are reviewed. The researcher’s ontological and epistemological perspectives have been framed and influenced by working as an NT practitioner with people affected by cancer, by a role in NT training accreditation and in professional regulation, and from a past career in mainstream life sciences. These four professional domains also served as points of reference for reflection during the design, execution and completion of the study.

Reflection by researchers is broadly accepted in qualitative work (Jasper, 2005, Clayton, 2013). However, there are caveats to its use (Waterman, 1998); reflective writing may be considered in some forms to be indulgent, narcissistic, confessional (Finlay, 2002), or, when read without prior explanation may even be irritating (Waterman, 1998). Furthermore, there may be risk to the reflector of close scrutiny of self, feelings and behaviour (Marsh, 2014), perhaps intensely personal writing may uncover neuroticism (Waterman, 1998), lead to negative mood states, or lead to reflecting on past trauma (Marsh, 2014). However, its use in training to encourage critical learning and professional development is widespread in healthcare, education and social work, as well as research (Clayton, 2013, Sharma et al., 2009, Heath, 1998, Nairn et al., 2012, Brown and Brown, 2011, Le Gallais, 2008, Thompson and Pascal, 2012). Reflection may take many forms and operate at different levels, from a technical perspective to solve practical problems (Thompson and Pascal, 2012), to critical self-reflection or reflexivity, which examines more deeply within the role of the researcher and their assumptions and personal beliefs (Jacobs, 2008). When undertaken critically, reflection may support transparency by exposing researchers’

experiences, frames of references, and cultural and ethical perspectives (Finlay, 2002). It has particular value for researchers from within the profession or community that is being researched and who may be considered to have an 'insider/outsider' identity' (Burns et al., 2012, Le Gallais, 2008). Researcher reflection may enable the implications of this duality to be examined (Hellawell, 2006), and to find a position that accommodates both identities (Burns et al., 2012). Critical reflection can be approached from a number of approaches. The overarching theoretical framework of reflection used in this study is the Mezirow model (Mezirow, 2000), underpinning a process of transformational learning (Kitchenham, 2008), to explore aspects of the journey of the researcher conducting the study reported in this thesis.

In summary, the design of the study reported in this thesis, as a mixed methods study within the pragmatic paradigm, is underpinned by consideration of the potential for incompatibility between the research methods combined. Rigour and credibility have been systematically considered and addressed, and the study design of a survey followed by interviews has been aligned to two typologies for the purpose of accurate and transparent communication. Theoretical aspects of the use of surveys to measure subjective phenomena such as attitudes, producing quantitative data and an indication of preliminary themes to inform the interview phase, have been considered. Potential approaches for collecting qualitative data including ethnographic observation, diary analysis and interview have been considered. Some potential problems in interviewing professional peers were identified and the use of telephone interviewing critiqued. Analytical approaches to qualitative data have been considered, and the experience of the researcher, the research aims, and the intended use of the research in policy development have guided the choice toward the use of Framework Analysis. Overall, these points of critical analysis provide a theoretical foundation for the study procedures, which will be described in the following chapter.

Chapter 3. Study procedures

This chapter describes the procedures used for collection and analysis of data, including the design, sampling, recruitment and administration of a survey, followed by in-depth individual interviews and one group discussion of a single issue that arose from the survey.

3.1 Ethical approval

The research programme was approved by the University of Westminster Research Ethics Committee (App. No. 12-13-17) (Appendix 1). Study participants received information about the project (Appendix 2). Survey respondents were provided with the information sheet at the start of the survey, and were asked to indicate their consent for their responses to be used by choosing to start the survey. Interview participants were provided with the information sheet before the interview, this was verbally restated by the researcher and participants were asked to give verbal agreement to consent at the start of the interview.

3.2 The Survey

The survey collected data to analyse professional characteristics of registered nutritional therapy (NT) practitioners and their perspectives on working with people affected by cancer. This section describes the structure of a self-administered, anonymous, on-line questionnaire and the types of data collected; it also describes how the survey design supported recruitment of participants for the in-depth qualitative phase of the research.

3.2.1 Survey Design

This section describes the design of the survey, including relevant literature providing guidance, the sequence of questions, the use of funnelling to collect data from different cohorts, and the nature of the data collected.

The survey design was informed firstly by research on optimising the effectiveness and accuracy of surveys. Guidance from two working groups on surveys of healthcare practitioners (Burns et al., 2008, McColl et al., 2002) provided advice on questionnaire design and piloting, question wording, sampling, survey recruitment, mode of survey administration and on statistical considerations of sampling. Consideration of sampling small populations was also noted (Draugalis and Plaza, 2009) and of social desirability effect (Krumpal, 2013). Other surveys of healthcare practitioners that investigated the use of information and evidence-based practice (Chiu et al., 2012, Leach and Gillham, 2011, Smith et al., 2005) or collected data on CAM practitioner characteristics (Bensoussan et al., 2004b) were also considered for design, sampling, administration and analysis.

The questionnaire (Appendix 3) contained thirty one questions, a combination of open-ended and closed questions (McColl et al., 2002) were used. See section 4.2.5.2 for details of analysis of text from open-ended questions. Section 1 of the questionnaire used nine closed questions to collect quantitative data on participant characteristics including practice arrangements (e.g. sole practitioner, multidisciplinary practice, National Health Service etc.), years in NT practice, levels of NT training and route of registration, other qualifications and other therapies offered, and their age and gender. Some questions offered a text box for responses in addition to pre-set responses. Multiple-choice questions on practice arrangements, other therapies practiced and training allowed more than one response to be selected, since it was anticipated participants may, for example, work in more than one type of practice. After responding to these questions, respondents were asked to indicate their position on working with people affected by cancer. Their response identified them as either:

Non-Cancer Practitioners (NCP) - who were not interested in cancer practice or who were interested but not yet working with people affected by cancer.

Cancer Practitioners (CP) - who were either specialist, or who saw a range of clients that included people affected by cancer.

This approach allowed for comparative data analysis between the self-identified groups and supported purposive sampling for participants in interviews in Phase 2. Survey participants who did not respond at this point exited the survey.

NCP participants were asked open-ended questions to ascertain if there were particular barriers to working with people affected by cancer, and resources or other support they felt might enable them to overcome those barriers. Any other comments on the practice of nutritional therapy for cancer were also collected.

The CP survey section contained eighteen closed and open-ended questions to collect quantitative and text data, as detailed here. Respondents were asked firstly about skills and knowledge needed for working with clients affected by cancer, and to identify specific training courses or resources they found helpful. The use of information in cancer practice was explored, including typical queries and difficult questions in practice, information resources referred to, usefulness of specific information sources and desired improvements. Perceived barriers to practice and the possible means to overcome them, and other desired improvements were explored with open questions. Data were also collected on the sources of client referrals and whether participants wanted to increase the number of clients they saw who are affected by cancer. At the end of the CP section, participants were invited to take part in further research, and if so to send their contact details by email separately from the questionnaire.

3.2.2 Questionnaire piloting

The draft questionnaire was piloted with four experienced NT practitioners selected for maximum variability (Patton, 2002) in practice settings, positions on cancer work and geographical locations. They were asked to review the draft questionnaire for clarity and appropriateness of questions, layout and sequence and it was revised in view of their comments to produce the final version (Appendix 3). The refinements suggested by the reviewers

(Appendix 4) were to clarify some wording, to expand the options for responses to the questions on practice arrangements and other healthcare training, and to ask an additional questions on routes of client referrals. Two suggestions from reviewers were not incorporated as they would have expanded the survey beyond the research aims and the agreed sample population.

3.2.3 Survey sample.

The survey was open to all registered NT practitioners in the UK, to recruit practitioners with expected standards of training and minimum standards of practice, defined by National Occupational Standards (NOS), as required for professional registration. The survey population was estimated at 600, based on information obtained from the CNHC and this agreed with the number of NT practitioners (total 618) on the previous voluntary register held by the Nutritional Therapy Council (NTC) in October 2009 (Granger and Watkins, 2014). The recruitment target aimed for a minimum response rate of 10% and was informed by other similar surveys of healthcare practitioners (Braun et al., 2013b, Leach and Gillham, 2011, Pring et al., 2012) and by data from a professional association on their members surveys (BANT, personal communication). Furthermore, guidance on sample size for surveys of small populations was followed (Draugalis and Plaza, 2009), which indicates minimum sample sizes that could be considered statistically representative. For a survey population of 600, in which a p value of 0.05 is used for statistical significance, a sample of 234 is needed.

The survey opened on 25th November 2013 and responses were monitored. The exact population size (the number of UK NT registrants) was obtained from the CNHC Registrar at two points during recruitment, and the survey closed on 3rd April 2014 when the target for apparent sample representativeness had been met.

Concurrently with the survey development, the NTC registration scheme was audited to provide data on the entire registrant body from 2006-2009, (Granger and Watkins, 2014). This was for comparison with the data on

demographics and practitioner training from the survey, as additional assessment of representativeness of the survey sample.

3.2.4 Survey administration, sampling and recruitment

This section describes how the survey was administered and how NT practitioners were recruited to participate. It details the measures taken to ensure broad coverage of publicity for the survey to maximise recruitment. The self-administered survey was hosted on Survey Monkey, an on-line, internet-based survey provider, which generates a web link to the survey location that can be posted on recruitment material, and provides pass-word protected access for researchers to access and download survey responses.

Multiple recruitment methods were used to reach the survey population of all UK registered NT practitioners, which also considered geographical coverage. The survey was promoted by the researcher in professional development workshops that were delivered live but were also recorded and available for later download (therefore total audience unknown). The formal launch of the survey on 25th November 2013 was announced in the British Association for Applied Nutrition and Nutritional Therapy (BANT) professional association newsletter and website, and on the BANT Linked In professional networking site, which all carried an electronic link to the questionnaire. This was followed up by emails to eight educational institutions that provided accredited NT training courses at twelve locations in England, Scotland and Northern Ireland (there were no colleges in Wales), to notify their staff and alumni. The recruitment notice was also sent to another professional association, the Wholistic Nutritional Medicine Society, to inform their members. A complementary therapy magazine 'CAM' and the voluntary regulator for the profession, the Complementary and Natural Healthcare Council (CNHC), were also asked to publicise the survey. A second reminder (Burns et al., 2008), was sent by email on 20th March 2014 to all BANT members and was posted on their Linked In site.

Paper copies of the questionnaire were also available by contacting the researcher by email or through Linked In.

3.2.5 Survey data management and analysis

In this section, the procedures for managing and analysing the data collected by the survey are detailed, including procedures for maintaining research rigour, data integrity and transparency in coding and interpretation.

3.2.5.1 Survey data cleaning, quality control and coding

All data were downloaded from the survey site onto a password-protected laptop, for analysis and data management using IBM SPSS (versions 21 and 23). The coding system was developed manually and is summarised in Figure 1. Survey responses were entered manually into SPSS as numerical codes from each participant's questionnaire.

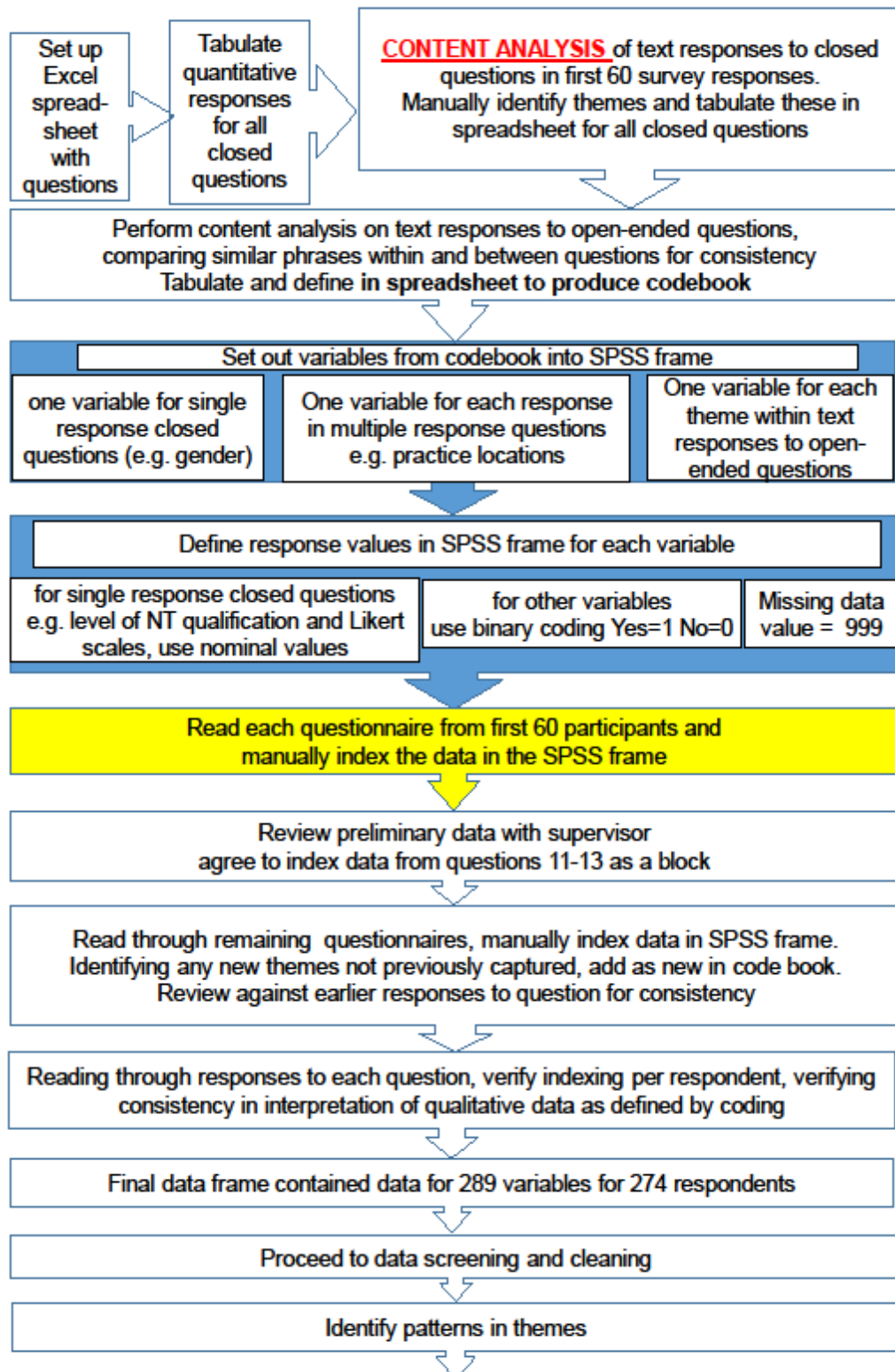


Figure 1. Development of code book and data indexing process

3.2.5.2 Development of the code book for survey data

This section describes how coding was developed and implemented for the survey data. Survey responses included categorical and numerical data generated by closed questions, text responses from closed questions that provided a text box for additional or alternative responses, and text responses to open-ended questions. The professional experience and knowledge of the researcher may influence text interpretation and coding (Graneheim and Lundman, 2004, Jasper, 2005, Burns et al., 2012). The researcher, therefore, first exposed and explored her presumptions, and documented anticipated themes arising in text data, recording these as a spreadsheet page appended to the codebook. This exercise was then used as a focal point for a reflection on the challenges of researching one's own profession as a researcher-practitioner or 'insider-outsider', reflecting on preconceptions of the research topic and her dynamic within it (Ortlipp, 2008), and potential implications of this duality roles, which has particular traction for professional doctorate researchers (Coghlan, 2007).

The codebook for survey data analysis was then devised using the first 60 questionnaire responses, laid out in an Excel spreadsheet, providing a coding system for categorical, numerical and text data. Binary coding was used to record whether participants did, or did not, give each response (Wigert et al., 2013). Missing data was coded 999 throughout. Single-response questions were each coded as a single variable, with each potential response coded as a different nominal value for that variable. Age was recorded as the numerical value given by respondents. Two questions that used Likert scales to rate information sources were each coded as a single variable, with coding values reflecting the Likert scale numerical responses of 1 to 5.

For multiple-response closed questions, and for all questions with text responses, each possible response was set up in the coding system and in SPSS as an individual variable. For example, the first question in the survey collected data on practice setting and respondents could indicate more than

one setting, therefore each possible setting was set up as a variable in the coding system and SPSS.

For coding text generated within survey, content analysis was conducted manually (Vaismoradi et al., 2013, Kondracki et al., 2002, Elo and Kyngäs, 2008, McKenna et al., 2017). Coding was developed deductively, first for text responses from closed questions in the first 60 responses, using content analysis.

Coding for text responses to open-ended questions was then similarly developed from the first 60 survey responses, producing a comprehensive set of text themes for each question. These were re-read, refined and then defined in the codebook. Subtle differences between similar themes were noted, and the essence of these were captured within the coding system, by re-reading text data in early survey responses and comparing them against later participants, with the aim of achieving consistency of coding for responses (Kondracki et al., 2002).

e.g. “lack of integration with oncology” as a barrier to cancer practice was differentiated from “medical opposition or resistance”

In the NCP section some responses relevant to the first two questions were given in response to the final ‘any other comments’ question, hence text responses from the three questions were analysed together,

The text analysis, codebook and coding process were reviewed with the director of studies as a measure of verification by peer-review (Burnard et al., 2008). Finally, the codebook was compared with the researcher’s reflective exercise on coding conducted before data analysis, to reflect on potential influence in interpretation in the coding system, as part of the reflexive journey of the researcher (Ortlipp, 2008).

The codebook covered 289 variables derived from 31 questions. Two-way data verification was conducted by firstly coding each participant’s questionnaire, and then working through each individual survey question and verifying the data entries for each response. This was a further measure to

achieve coding consistency by comparing coding for responses from different participants (Elo and Kyngäs, 2008, Thomas and Magilvy, 2011).

Preliminary themes were identified in the text data by reviewing the codes and grouping together similar codes from the content analysis. These preliminary themes were used to inform the design of the in-depth qualitative phase of research. In further analyses of preliminary themes emerging from text data, CP respondents were stratified according to their additional training, to analyse if there was any association between other training they may have and their views of skills and knowledge considered important for cancer practice. Themes from respondents with additional health and life science training were compared with those from respondents with other training or none, then comparisons were made between practitioners based on whether they also provided counselling, coaching or other psychological practice.

3.2.6 Statistical Analysis

In this section, the statistical methods used in the analysis of quantitative data from the survey are described. The exact number of NT practitioners on the UK register at the close of recruitment to the survey was confirmed by CNHC Registrar. From this, the percentage of the survey population recruited was calculated. Question response rates and time taken to complete the survey by respondents were analysed from data downloaded from the survey service.

Analysis of demographic and practitioner characteristics data was conducted, taking account that responses to all survey questions were optional. Percentage frequencies of practitioner characteristics were, therefore, analysed for the entire survey sample. Practitioner characteristics were then compared between NCP and CP cohorts to identify possible statistically significant differences between practitioners who differ in their position on cancer practice. The frequencies calculated were for actual responders, (excluding non-responders), for consistency, since there were some differences in response rates to questions.

Pearson's chi-squared test (Peat, 2008) was used for the following variables: age, gender, years in practice, registration route, academic level of NT qualification, and academic level and subjects of other qualifications. *P*-value of <0.05 was considered significant. Fisher's exact test was used to re-test very small samples for statistical significance.

Likert scale data were analysed to produce mean, median and mode (Sullivan and Artino, 2013).

To further assess the representativeness of the survey, data on four variables were compared with data from an audit of the entire Nutritional Therapy Council (NTC) 2006-2009 register, which had collected a complete set of verified data on age, gender, years in practice, training and route to registration, of all 618 UK NT registrants up to October 2009 (Granger and Watkins, 2014). Pearson's chi-squared test was used and *P*-value of <0.05 was considered significant. Statistical comparison took account of differences in data collection between the two data sets. The NTC data comprised 100% response rates for the variables used in the comparison, whereas this study survey allowed participants to decline answers, therefore data for actual survey responses was used, discounting missing data.

3.3 Interviews

This sections describes the procedures for collecting and analysing qualitative data by interview. Semi-structured interviews, (Dicicco-Bloom and Crabtree, 2006), conducted by telephone (Miller, 1995, Mealer and Jones, 2014, Smith, 2005, Musselwhite et al., 2007, Cachia and Millward, 2011), were used to explore NT practitioners' perspectives on working with people affected by cancer. Preliminary themes emerging from the survey data informed the framework of the interviews, and a single group interview as a consensus panel (Coreil, 1994) was used to explore one specific emergent preliminary theme.

3.3.1 Sampling for Interviews

Participants for interviews were recruited in several ways.

Purposive/purposeful sampling (Patton, 2002, Suri, 2011, Palinkas et al., 2015) was applied, aiming for maximum variation in years in practice; level of NT training; training in other subject and geographic location to reflect the data from the survey (Querstret and Robinson, 2013). Quota sampling was applied for gender (Robinson, 2014). Six participants self-identifying as CP in the survey volunteered for the qualitative research phase by emailing their contact details to the principal investigator. Seven further CP participants were then recruited by the researcher via being approached at professional events.

Eight NCP participants were recruited, of these, one had been involved in reviewing the survey questionnaire at the pilot stage. Four practitioners spontaneously volunteered after taking part in the survey, through personal contact at professional events and a further three NCPs were recruited by direct approach by the researcher to registered practitioners listed with the professional association BANT, based on geographical location, training and years in practice.

The order of interviews, conducting all except one CP interviews first, allowed the NCP interview guide to be developed from the themes of the CP data. The thirteenth CP was interviewed later due to that participant's availability.

3.3.2 Themes explored in interviews

For CP interviews, the overall approach was informed by research on interviewing colleagues and peers, particularly with regards to the 'insider' identity advantages of rapport and cultural understanding, the impact on social desirability effect, and questions of 'expert judgement' (Mercer, 2007, Mealer and Jones, 2014, McDermid et al., 2014, Chew-Graham et al., 2002). The challenge for the researcher of moving from clinical interviewer to research interviewer was also reflected on (Hunt et al., 2011). The themes

were informed by predominant preliminary themes emerging from the survey data (Chapter 4). An iterative approach to developing the interview structure was adopted; themes emerging from analysis of the transcripts were reviewed to identify if new themes were emerging that needed to be added to the interview guide. This enabled further exploration of new themes emerging from practitioners' perspectives that may not have emerged from the survey data.

The interviews with CP sought to explore themes within the lived experience of practicing nutritional therapy with people affected by cancer, and the participants' perspectives on the professional framework within which this work may take place. Themes that were explored, indicated by data from the survey, were:

- i) practical and material aspects of working with people affected by cancer, including an overview of the participant's practice arrangements and their use of information and other knowledge resources.
- ii) professional underpinning of practice by education and training were explored, their perceived needs for developments in training, and extent of professional experience in cancer practice.
- iii) motivation and reward in cancer practice, and challenges and barriers to practice and how they might be overcome. (CP Interview guides, Appendix 5)
- iv) Themes explored with NCP (Appendix 6) were informed by the preliminary themes emerging from the NCP section of the survey, which collected data on reasons for not working with cancer patients and factors that might support them to start cancer practice. The interview guide was also informed by themes emerging from the CP interviews including challenge to practice identified by CP.

3.3.3 Interview data collection

In this section, the process of conducting semi-structured telephone interviews is detailed (Cachia and Millward, 2011). Individual participants gave informed consent and were interviewed by appointment, the call was recorded and then transcribed. One group interview was held in person, recorded and transcribed.

3.3.3.1 Individual interviews

Participants were sent an interview guide (Appendices 5 and 6) before the interview took place, and a summary of the themes to be explored was given verbally when the interview was arranged. Interviews were conducted by telephone, and recorded using an Olympus digital sound recorder DS-30 with telephone earpiece.

At the start of each interview the participant was reminded that the process was completely confidential, that no personal identifiers would be attached to their data or extracts from it, that there were no 'correct or incorrect' answers to the questions, that they could decline to answer any or all questions and terminate the interview at any time. Consent was given verbally after participants had read the interview guide and after this briefing. The interviewer maintained a position of neutrality (Quinney et al., 2016), and interviewees were asked to assume that the interviewer had no prior knowledge of them or their perspectives, so that their perspectives were completely articulated in the interview and recorded. The interview guide was used to prompt the conversation, but new themes that were raised by the participant were pursued as they wished, to enable them to explore their perspectives as openly and fully as possible.

Recordings were downloaded as an MP3 file onto a password protected laptop. Each interview was transcribed by a professional transcription agency, using a secure upload facility to send each file to the agency. Transcripts were returned by the agency as password-protected Microsoft Word files, which were stored on a password-protected laptop. Files were

identified by an alphanumeric file name, the list of filenames with the identity of the corresponding participant was kept separately in a locked cupboard.

Each recording was reviewed by the researcher to critically evaluate the interview technique to identify improvements, and to identify new areas that may deserve deeper exploration in further interviews.

3.3.3.2 Group interview procedure and theme

A preliminary theme emerging from the survey data was a desire for practice guidelines for working with people affected by cancer. Professional associations may provide practice guidelines for their members, covering areas of practice such requirements for practice premises, obtaining and recording client consent, or working with specific groups of clients. Therefore a committee of practitioners within an NT professional association agreed to discuss the provision of practice guidelines for people affected by cancer as a group discussion. The committee's previous guidance to members on cancer practice was provided to the researcher. The group discussion brief was reviewed with the committee chair beforehand, and confirmed by email the day before (Appendix 7). The discussion took place in their scheduled meeting, facilitated in person by the researcher, with one committee member participating at a distance by video link. The research aims and objectives were summarised and consent to participate given verbally by the meeting attendees. The discussion was recorded, transcribed and analysed following the same procedure as the individual interviews.

3.3.4 Qualitative data analysis of interviews.

This section details the procedures for analysing qualitative data from transcripts using thematic analysis following Framework methodology (Ritchie and Lewis, 2003, Smith and Firth, 2011, Gale et al., 2013) with nVivo (version 11) used for data management. Framework methodology, which was developed for research aimed at developing policy, follows five stages to identify, organise and analyse themes emerging from qualitative data. As

detailed below, the first stage is familiarisation with the data, followed by the second stage, development of a theoretical framework and coding system. This combines deductive analysis, driven by the interview topics, and inductive analysis, as new themes, sub-themes, and categories (units of meaning) within them emerge from the interview transcripts. These were applied in the process of indexing, which attaches codes to themes, sub-themes and categories emerging from the data. After indexing all of the transcripts, the process of charting was used to condense the data, by constructing framework matrices which summarise themes for each individual case, to enable critical analysis. Differences in participants' perspectives on each major theme were compared and contrasted, in the fifth Framework stage of synthesising the data (Ritchie and Lewis, 2003). Researcher reflection (Chapter 11) took place during the development of the thematic framework by examining assumptions about the meaning of putative themes emerging from the data.

3.3.4.1 Interview data cleaning, quality control and anonymization

Each transcript was read through first and compared with the audio file. A small number of transcription errors of predominantly technical terms were detected and corrected. Any identifiers were removed from the transcript text. Analysis was conducted after each individual or occasionally two interviews. Records of all data entries, theme and category creation and modification, case indexing, framework matrix entries and editing, were detailed in the nVivo project event log.

3.3.4.2 Framework Analysis stage 1 – familiarisation with data.

The first two CP interviews were listened to twice and their transcripts were printed out and read through several times. A preliminary thematic analysis was conducted first on paper, highlighting themes and sub-themes and categories within them in the text. Moreover, this was to enable immersion in the data, to 'find the flavours' of these early participants' perspectives on cancer practice. Preliminary notes and reflective notes were made on these

early emergent themes, before setting out the data analysis framework and conducting further interviews. Each subsequent interview was reviewed after transcription as an audio file, and read through several times in entirety before ascribing codes to the data.

3.3.4.3 Framework Analysis stage 2 – development of thematic framework.

The analytical scheme was then developed as a framework of themes (Ritchie and Lewis, 2003), providing a system for coding or indexing each participant's narrative against a set of themes, sub-themes and categories within them. The preliminary structure of themes was set out deductively from the topics in the interview guide, laid out in an nVivo file. Each theme was created within the nVivo file as a 'theme node', this provided a thematic skeleton which was expanded and elaborated as analysis proceeded. Initial sub-themes and categories within these main themes were set out from the preliminary analysis of the first two transcripts. Additional themes, sub-themes and categories were identified as they emerged from the data, so that the coding system was expanded as further transcripts were analysed and then indexed (see section 3.3.4.4, below). A degree of inductive analysis was therefore taking place within a coding scheme that was established deductively from the topics in the interview guide (Gale et al., 2013). Since the thematic framework evolves during the process of analysing subsequent transcripts, there was comparison between and within transcripts, to refine the thematic framework and ensure consistency of analysis across the data.

3.3.4.4 Framework Analysis stage 3 – indexing the data.

As described in section 3.3.4.3, development of the thematic framework and indexing the data against it take place bi-directionally.

Indexing was conducted as follows: each successive interview transcript, as a Microsoft Word document, was read through twice before analysis, then uploaded into nVivo as a 'case node', identified by its file number. The indexing (coding) process for each transcript was conducted manually within

the nVivo workspace (Smith and Firth, 2011). The transcript text was loaded into a window on-screen alongside the thematic structure. The transcript was worked through and each thematic unit of meaning was identified in the text, highlighted with the mouse, and assigned to (indexed to) a category within the structure of themes and sub-themes. As described in 3.3.4.3, new themes, sub-themes and categories were added as required to the thematic framework. As each new transcript was analysed, earlier transcripts were re-read to compare text for the same theme from different participants.

The use of nVivo to manage and organise data in this way enabled comparison of text indexed against each theme, sub-theme and category, due to linkage between the theme and text that has been indexed to it. Blocks of text within each transcript could also be indexed against several themes, sub-themes or categories, since the interview transcript remains 'intact' but linked within the nVivo system to each theme node that it had been indexed against. The on-screen view identified the number of cases (participants) and blocks of text indexed against each theme, sub-theme and category. This facilitated vertical (between cases) and horizontal comparison (between themes) of the entire data set. It also enabled drilling down through themes, sub-themes and categories, whilst retaining the integrity of participant narrative.

Participant characteristics, including gender, training background including NT and other qualifications, years in practice, geographical location, and practice arrangements, were indexed within the scheme of themes and categories. To enable further analysis, these were also recorded within nVivo as case attributes for each participant. This provided a separate record to support the intent of maximum variability sampling for the interviews and it enabled comparison of the characteristics of the interview cohorts against the survey cohorts. It also facilitated further data analysis within the interviews by using filtering for specific practitioner attributes within the data file.

3.3.4.5 Framework analysis stage 4 – charting in framework matrices

When all transcripts had been indexed to themes and categories, the process of charting was undertaken to develop framework matrices, to summarise and condense the indexed data (Ritchie and Lewis, 2003, Smith and Firth, 2011). A framework matrix was developed for each main theme in the analytical scheme, this provided a structure within which the data could be critically analysed. Each matrix contained horizontal rows for cases, and vertical columns for each sub-theme and category within the theme. It was therefore essentially a linked spreadsheet that summarised each theme, for each case that has discussed that theme.

To set up a matrix for a theme, the sub-themes and categories within it were each laid out at the head of a vertical column, using the framework matrix format within the nVivo workspace (Smith and Firth, 2011). Each case that had been indexed to that theme was then linked into the first cell of a horizontal row within the matrix. The actual text that had been indexed was viewed on-screen alongside the matrix. Working across the matrix columns for each case, a summary of the data for each sub-theme and category emerging from their narrative was manually entered in the appropriate cell in the matrix. Therefore the matrix contained a horizontal row for each case, with a summary of their data for the theme, as indexed to sub-theme and categories, in the appropriate vertical column. Reading the matrix horizontally enabled review of the case, reading vertically enabled review of each category within themes and sub-themes. Cells in the matrix were populated by a summary of the data from each case for each category, and would be left empty where no data was collected for that case for a specific category. Linkage of the data summary within the matrix, to the raw data in the transcript, was visible within the nVivo workspace, by thematic highlighting of the text. Although Framework analysis can be done using uncoded transcripts without thematic coding of the transcript first, the process of coding each transcript first, and then summarising in the matrix, was adopted as part of the quality assurance process and to underpin in-depth analysis (Gale et al., 2013, Ward et al., 2013).

Separate framework matrices were developed for CP and NCP themes and common matrices were developed to enable comparison between CP and NCP perspectives on major themes, for example “practice workload”.

3.3.4.6 Framework analysis stage 5 – mapping and interpretation

Notable quotations or highlights from transcripts were identified during the framework analysis process and were recorded as memos within the nVivo workspace, linked to the corresponding case. The data summarised within the frameworks were reviewed and critically analysed, comparing individual perspectives on themes and identifying differences between cases, and identifying common threads of meaning. Perspectives on “specialist cancer skills” contrasted the lived experience of CP participants, with the perspective of NCP reflecting on the skills they felt they would need to acquire to start working with people affected by cancer. Examples of perspectives on each theme were drawn from the matrix and the original transcripts to illustrate the spectrum of participants’ views, identifying contrasting and contradictory perspectives.

3.4 Quality assurance procedures

This section summarises the quality assurance procedures incorporated in the survey and the interview phases, and overall to underpin the integrity of the study

Firstly, within the survey, as described in 3.2.5.2, the coding system including content analysis of text, code book development and coding process of the survey data were reviewed with the director of studies, during development and during application to the survey data. Secondly, two-way verification of data entries for the survey data from each respondent was implemented, by working through each question and checking the individual responses.

For the interview and focus group data, the coding process and Framework matrices were reviewed during development and implementation with the director of studies. The initial coding of interview transcripts, before charting

in the framework matrices, underpins an auditable trace of the analysis of themes in the interview data.

3.5 Cross references between phases

As a mixed methods study, data from the survey informed the framework and direction of the exploratory qualitative interview phase (Leech and Onwuegbuzie, 2009, Feilzer, 2010). Firstly, professional characteristics data from the survey sample and of the survey cohorts, CP and NCP, were used to define targets for purposive sampling for interviews. Comparison of professional characteristics data between the survey sample and the interview sample was conducted during recruitment for interviews as part of the study procedure, at the conclusion of data collection, and during data analysis.

Secondly, preliminary themes emerging from text responses from the survey, generated in response to open-ended questions, informed the direction of the interviews and focus group. These preliminary themes from the survey were then compared with themes emerging from the interviews, at several points between individual interview and during data analysis. Differences in perspectives were identified, and new themes emerging from the interview data that were not extant in the survey data were identified.

The theme of the single group interview was informed by a predominant preliminary theme emerging from the survey data, and the data from the group interview was compared back to the survey data during data analysis.

3.6 Reflective research diary

A reflective research diary was kept throughout the design and implementation of the study. Reflection was used to facilitate critical analysis of beliefs and biases that may impact on the research design, data collection and analysis, and to support development as a researcher.

The overarching theoretical framework of reflection used was that of the Mezirow model (Kitchenham, 2008) underpinning a process of

transformational learning. Using this framework therefore, and using notes in the research journal, critical reflection has taken place at key stages in the research journey; including during the research training modules, after some supervision sessions, particularly when barriers to progress are experienced, before and during data analysis and interpretation, and particularly on the specific dimensions of ethics and the tensions between researcher and other roles. These reflections are written in the first person for authenticity (Chapter 10).

In summary, this chapter describes the design and operation of a mixed-methods doctoral study to explore, for the first time, the perspectives of NT practitioners on working with people affected by cancer. A self-administered anonymous on-line survey collected previously undocumented data on NT practitioner characteristics and their preliminary perspectives on cancer practice. These data informed the design and implementation of the exploratory qualitative phase, and a group interview explored one preliminary theme emerging from the survey. Individual interviews with NT practitioners explored in-depth, for the first time, their perspectives on working with people affected by cancer to inform future professional development needs.

Interview data was analysed using the Framework Analysis method, using a combination of deductive and inductive methods to identify units of meaning in the data, to which codes are assigned. From this analysis, major themes in practitioner perspectives have emerged. Throughout the study, the researcher used a process of critical reflection to examine the impact and dynamics of the professional doctorate researcher conducting research within their own area of professional practice.

Chapter 4. Phase one results – the survey

This chapter describes the data collected from the survey of UK registered nutritional therapists. The survey collected data on NT practice arrangements, training, and years in professional practice, and enabled respondents to be allocated to one of two groups, those who do work with clients affected by cancer (CP) and those who do not (NCP). This enabled comparison of the professional characteristics between the two groups, and some differences in training and experience were identified. Preliminary perspectives on working with people affected by cancer were collected from both groups within the survey, which informed the qualitative research in Phase Two.

4.1 Survey response rates

Responses were received from 274/888 (31%) NT practitioners.

Since no survey questions were mandatory, response rates to individual questions varied from 22%-99% (Appendix 3, Questionnaire). The highest response rates were for the closed multiple choice questions on practice arrangements (Question 1) (272/274, 99%), NT training (Question 5) (250/274, 91%) and registration route (Question 3) (249/274, 91%). The question with the lowest response rate in the survey (37/165, 22%) was an open-ended question asking NCP respondents to give reasons why they do not work with people affected by cancer (Question 11). However, when this NCP cohort was asked to suggest factors that might enable them to start working with people affected by cancer, 121/165 (73%) provided a response (Question 13).

4.2 Demographics and practitioner characteristics

This section describes the characteristics of registered NT profession in the survey sample, See Table 1.

Table 1. Characteristics of survey cohort of registered nutritional therapists

Variable	Survey data n=274 (% participants)
Age (years)	Mean 47.6, Median 48 Range 22-71
Gender	
Female	238 (87%)
Male	9 (3%)
Not stated	27 (10%)
Years in practice	
Less than 5	118 (43%)
5-9 years	59 (22%)
10 or more years	38 (14%)
Not stated	59 (21%)
Registration Route	
Accredited qualification	149 (54%)
Portfolio application	40 (15%)
Qualification mapped to NOS	26 (9%)
Unaccredited qualification	13 (5%)
Can't recall/route changed	21 (8%)
Not stated	25 (9%)

NT qualification	
Diploma / foundation degree	134 (49%)
Degree	79 (29%)
Post-graduate diploma	11 (4%)
Master's degree	26 (9%)
Not stated	24 (9%)
Other qualifications, academic level†	
Diploma / foundation degree	50 (18%)
Degree	126 (46%)
Post-graduate diploma	43 (16%)
Master's degree	45 (16%)
MPhil/PhD	5 (2%)
Not applicable	23 (10%)
Not stated	50 (18%)
Other qualifications, subject†	
Health and life sciences	73 (27%)
Social sciences and education	41 (15%)
Business, law, communications	40 (15%)
Humanities	27 (10%)
Other Complementary and Alternative Medicine (CAM) subject	27 (10%)
Chemistry, physics, engineering, maths	16 (6%)
Not stated	84 (30%)
Other therapies practiced†	
Counselling, psychotherapy, coaching	32 (12%)
Naturopathy	21 (8%)
Aromatherapy, reflexology, massage, other bodywork*	21 (8%)
Other CAM professions not listed	18 (7%)
Exercise, fitness and weight management	15 (6%)
Healing, Reiki	8 (3%)
	6 (2%)

Herbal medicine other than Chinese	6 (2%)
Homeopathy	3 (1%)
Medicine, dentistry, pharmacy, veterinary medicine	3 (1%)
Nursing, midwifery	2 (1%)
Chiropractic and osteopathy (not included in other bodywork, as regulatory arrangements are different)	2 (1%)
Acupuncture, Chinese herbal medicine	1 (<1%)
Physiotherapy	0
Not stated	160 (58%)
Practice setting†	
Sole practitioner	220 (80%)
Multidisciplinary practice	85 (31%)
CAM centre or service	21 (8%)
Private medicine facility	15 (6%)
Group nutrition practice	10 (4%)
Training institution	5 (2%)
Advisory service, health charity	3 (1%)
NHS	2 (<1%)
Working from home	1 (<1%)
Hospice	1 (<1%)
Not stated	2 (<1%)
†Participants may indicate more than one response for practice location, other therapies practiced, and other qualifications. CAM - Complementary and alternative medicine.	

The data in Table 1 provides a profile of the survey cohort, which has a mean age of 47.6 years, and 96% female of those identifying a gender. 36% participants indicated they had been in practice for five years or longer. 49% practitioners reported having NT diplomas or foundation degrees, others had degree or post-graduate level NT qualifications. Notably, 73% (201) participants recorded other higher education qualifications, most commonly in other health and life science (HLS) subjects, which did not include other

CAM subjects. 42% respondents practiced other healthcare modalities including CAM, the most common being coaching and counselling (12%).

80% (220/274) respondents reported working as sole practitioners at least some of the time, of which 54% (148/274) worked exclusively as sole practitioners. Two participants reported working in an NHS facility. The potential implications of these working arrangements are explored further in the survey data and the individual interview data.

4.2.1 Comparison with historic data set for NT profession.

This section outlines the comparison between the survey cohort characteristics data and an historic data set which included the entire registered profession for a three year period from ending October 2009. Access to this data in which demographics, identities and qualifications were individually verified for the purposes of registration (Granger and Watkins, 2014), enabled comparison of four characteristics. Firstly the age and gender data were compared to assess the representativeness of the survey sample for those two parameters, and secondly to compare data on training, particularly since the availability of accredited training courses has increased in the years between the two data sets.

The mean age of this survey cohort was 47.1 years, range 22-71, compared with mean 45.1 years and range 25-73 years in the NTC data from three years earlier, and there were 94% female registrants in the historic data set, compared with 96% female of those identifying a gender in this survey.

Comparing practice experience and training data from the survey with data from the Nutritional Therapy Council (NTC) register for 2006-2009, identified two potential differences that may reflect changes in training accreditation. In this current survey sample there were significantly more practitioners with accredited qualifications (60% vs 10%, $p < 0.00001$), and more practitioners with less than 5 years in practice: (55% vs 39% $p < 0.001$), compared with the 2006-2009 data set.

4.2.2 Extent of NT practice with people affected by cancer.

This section will address first the data on practitioners' self-identification on working with people with cancer.

Respondents could choose from one of four descriptions:

"I am not interested in, choose not to work with people affected by cancer."

"I'm interested or willing to undertake cancer work, but not active with cancer clients at present"

"Active in cancer work, but this is not the only clinical area I work in"

"I consider myself a specialist cancer NT practitioner"

or could provide a comment in an open text box, which could also be used for additional comment. The first two descriptions were considered to indicate NCP, the third and fourth responses allocated participants to the CP cohort. Some respondents selected a description and provided additional text, from which preliminary themes were identified by content analysis. If their text comments appeared incongruent with their choice of description they were remained assigned by their choice of description, rather than being reassigned to a different category based on their additional text response. Eleven respondents only provided a text response, they were allocated to one of the four descriptions after content analysis where possible, but text-only responses from five survey respondents could not be clearly assigned to an NCP or CP description, they were counted as 'ambiguous'.

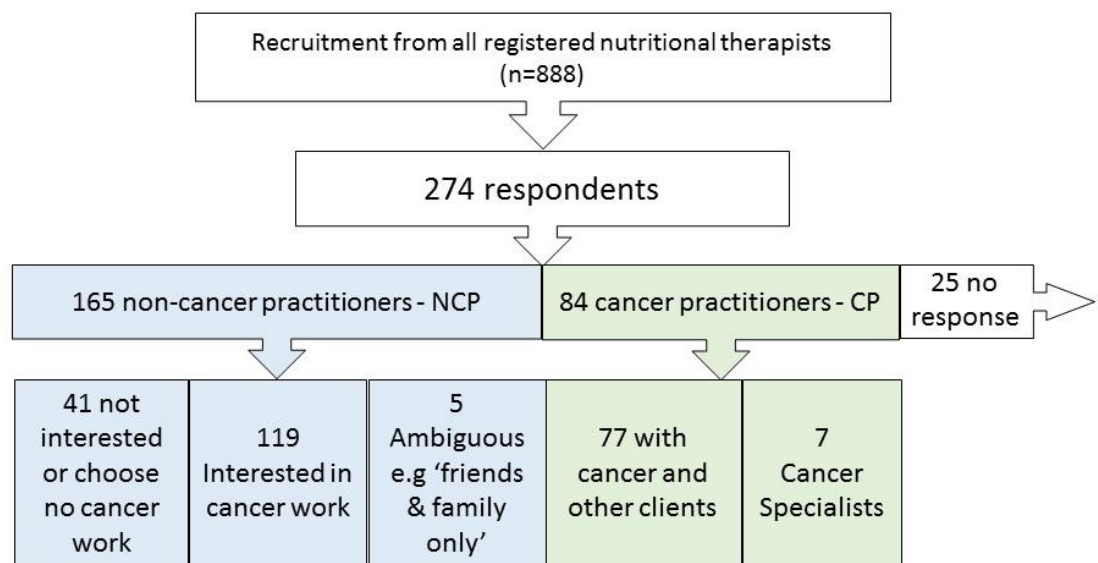


Figure 2. Extent of nutritional therapy practice with people affected by cancer

As represented in Figure 2, 91% (249/274) respondents identified their position on working with people with cancer. Examples of comments are shown, with the participant's identification of position on cancer practice where given.

"I work with 2 clients who are in remission from breast cancer (one of whom that has been diagnosed 3 times). Never worked with clients with an active diagnosis."

Participant 40, CP/NCP not identified.

"I am happy to help and support people with cancer, but I think it is a minefield and I don't feel comfortable with doing anything other than recommending a healthier diet or I would recommend NTs that I know have experience working with cancer patients."

Participant 237, CP/NCP not identified.

Some respondents self-identified as CP but described a limited practice, indicated they work only with relatives or friends affected by cancer, not fee-paying clients, or only work with people in remission from cancer.

Choice: Active in cancer work, but this is not the only clinical area I work in

Additional text: "Need to clarify here. I haven't practiced with a paying client but I have been working with my terminally ill friend over the last year. I have access to a lot of information provided by cancer specialists in terms of nutrition as I am actively working for my friend in attempting to keep her cancer stable..."

Participant CP259

Conversely, other respondents selected an NCP description but in additional text indicated they also work with people after a cancer diagnosis, or identified that they may work with relatives or friends affected by cancer but do not seek fee-paying clients,

Choice: I'm not interested in, or I choose not to work with people affected by cancer

Additional text: "In practice less than 1 year. Would not refuse to support a cancer patient with nutrition but would not seek cancer patients or offer to work with any refusing conventional care as well"

Participant NCP119

These responses revealed that practitioners perceived "cancer practice" as more of a spectrum than a binary concept, to be done or not done.

In summary, 31% (84/274) survey respondents self-identified as CP, of whom seven considered themselves cancer specialists. 56% (154/274) self-identified as NCP and a further 11 were allocated to the NCP cohort based on content analysis of their text only response, therefore 60% (165/274) were-identified as NCP. Of these 72% (119/165) indicated interested in cancer practice. Preliminary themes from the survey, and later individual interview data, explore further some of the factors that may enable them to do this.

4.2.3 Characteristics of Cancer Practitioners (CP) and non-cancer Practitioners (NCP).

This section describes the statistical comparison between practitioners who work with people affected by cancer and those who do not. Pearson's chi-squared test was used to determine whether there were any statistically significant differences in characteristics of CPs and NCPs (see Table 2). Differences in two practitioner characteristics between the CP and NCP cohort were identified: additional qualifications and years in practice. CPs were more likely than NCPs to have additional qualifications in other healthcare and life science disciplines, not including other CAM disciplines, (52% vs 32%, $p=0.009$). CPs were also more likely than NCPs to have been in practice for 10 or more years (26% vs 13%, $p=0.012$), and less likely to have been in practice for less than 5 years (43% vs 61%, $p=0.011$). A third apparent difference, working in a CAM centre, was too small to be considered meaningful.

Table 2. Comparison of key professional characteristics between Cancer Practitioners (CP) and Non-cancer Practitioners (NCP)

Characteristics	CP	NCP
Nutritional therapy qualification	n = 84	n = 161
Diploma or Foundation degree (FdSc)	45 (54%)	86 (53%)
Bachelor's degree	24 (29%)	55 (34%)
Post-graduate diploma	2 (2%)	9 (6%)
Master's degree	12 (14%)	14 (9%)
Level of other qualifications†	n = 74	n = 148
None/not applicable	4 (5%)	19 (13%)
Diploma or foundation degree	13 (18%)	37 (25%)
Bachelor's degree	43 (58%)	83 (56%)
Post-graduate certificate or diploma	16 (22%)	25 (17%)
Master's degree	16 (22%)	29 (20%)
Research degree MPhil/Doctorate	2 (3%)	3 (2%)
Subject of other qualifications†	n = 64	n = 125
Health and life sciences* (p=0.009)	33 (52%)	40 (32%)
Physical sciences, engineering, maths	5 (8%)	11 (9%)
Business, law, communications	12 (19%)	28 (22%)
Social sciences, education	13 (20%)	28 (22%)
Arts and humanities	9 (14%)	18 (14%)
Complementary therapies	8 (13%)	18 (14%)
Practice Setting†	n = 84	n = 163
Sole practice	70 (83%)	127 (77%)
Multidisciplinary practice	30 (36%)	53 (32%)
CAM centre* (p=0.001)	14 (17%)	7 (4.2%)
Private medicine	8 (9.5%)	7 (4.2%)
Group NT practice	6 (7.1%)	4 (2.4%)
NHS	2 (2.4%)	0
Advice service e.g. health charity	2 (2.4%)	1 (0.6%)

Training Institution	1 (1.2%)	3 (1.8%)
Works from home	0	1 (0.6%)
Hospice	0	1 (0.6%)
Other therapies practiced†	n = 43	n = 61
Acupuncture/Chinese Medicine	0	2 (3%)
Aromatherapy/Reflexology/Massage	9 (21%)	11 (18%)
Chiropractic/Osteopathy	0	2 (3%)
Coaching/Counselling/Psychotherapy	16 (37%)	14 (23%)
Dentistry/Medicine/Veterinary medicine	1 (2%)	2 (3%)
Healing	3 (7%)	5 (8%)
Herbal medicine	1 (2%)	3 (5%)
Homeopathy	3 (7%)	3 (5%)
Naturopathy	10 (23%)	8 (13%)
Nursing/midwifery	3 (7%)	0
Other HCPC professions	0	1 (2%)
Other CAM	7 (16%)	11 (18%)
Sports, fitness, weight management	4 (9%)	10 (16%)
Years in NT Practice	n = 72	n = 142
Less than 5 years* (p = 0.011)	31 (43%)	87 (61%)
5-9 years	22 (31%)	37 (26%)
10 or more years* (p = 0.012)	19 (26%)	18 (13%)

† Participants may indicate more than one response for practice location, other therapies practiced, and other qualifications. Statistical calculations used data from actual responders.*Statistical significance was set at $p < 0.05$

FdSc – Foundation Science degree

HCPC -Health and Care Professions Council

In summary, practitioner characteristics data enabled a profile of this cohort of UK registered NT profession to be documented, with the extent and context of cancer practice. These data highlight some key differences in

additional qualifications and duration of professional practice between practitioners who do and do not work with people affected by cancer.

Any respondent who self-identified as a CP was directed to a further section of the questionnaire to collect data on their perspectives of working with people affected by cancer. These data are reported in section 5.4. Data from the separate survey section for NCP respondents are presented in section 5.6.

4.3 Cancer practitioner perspectives on skills and knowledge for practice

This section documents preliminary themes emerging from CP respondents perspectives of the skills and knowledge that are considered important for working with people affected by cancer, and secondly how these skills and knowledge were acquired by respondents.

83% (70/84) CPs responded to the question on important skills and knowledge, text responses were analysed using content analysis (Seale and Silverman, 1997, Kondracki et al., 2002) . Reviewing the data identified skills and/or knowledge that respondents considered important that could be grouped into three broad themes, these were: technical and clinical skills and knowledge, interpersonal skills, and inter-professional skills. Firstly, technical and clinical knowledge and skills were cited most often by respondents to this question. Examples included skills, such as food skills, and knowledge, such as research knowledge, as exemplified in these responses:

*“Awareness of underlying imbalances that may be involved in cancer.
Awareness of eating problems that occur as a result of cancer
treatment.
Awareness of possible emotional states of clients with cancer
/recovering from cancer.
Awareness of other health problems that arise form (sic) cancer
therapies.”*

CP137

*“Scientific understanding
Research knowledge
practical skills - cookery / foods”*
CP67

*“understanding of functional approach
understanding that we are aiming to support our client nutritionally in
her/his journey NOT to "cure" the condition - and ensuring that client
understands this too
knowing where to find latest research / information = having good
sources of info”*
CP21

The second group of important skills and knowledge for cancer practice that could be identified in the data was the interpersonal skills used by the practitioner in their interactions with clients. These included coaching and communication skills, and the ability to show empathy and sensitivity, as exemplified in these responses:

*“Understanding- cancer patients are very scared and are unreliable
due to the nature of the condition
Extra careful- it is important to understand the impact nutritional
intervention can have on treatment
Collaborative- You need to work with the patients oncologist and keep
them informed. Manage expectations- mustn't claim to cure, treat or
make any difference to the cancer. Our role is in quality of life and
symptoms management.”*
CP261

*“Communication skills are of course vital, to be able to display
empathy and understanding Knowledge and training are key in this
area, as it really depends what stage of treatment they are at
Listening - what does the client want? Are they looking to support
optimum health long term, something to support their ability to
manage treatment?”*
CP247

*“Ability to communicate
Knowledges of biochemistry and biochemical function
Knowledge of physiology
Ability to listen
Patience and tolerance
Ability to be able to think outside of the box
Team player.”*
CP59

Within this group of interpersonal skills, the ability to access, assess and communicate evidence in practice was considered by respondents to be important. This uses interpersonal skills and also overlaps with the technical/clinical skills and knowledge. This response exemplified this intersection between the two skill sets:

“Broad knowledge of the published medical scientific literature in this field. I think practitioners need to be able to give an overview, ie, to talk about areas with the largest evidence base, and to be able to differentiate between hype (created by companies wanting to promote particular products), and actual, valuable research. Patients often arrive having read about one particular (often very expensive) supplement. We need to be able to put that in context. Practitioners need to be as confident as possible in their knowledge, as they may well be questioned by patient's relatives or oncologists.”
CP38

Finally, the third area of skills and knowledge that some CP respondents considered useful in practice related to inter-professional engagement and relationships in healthcare. Contrasting perspectives within this preliminary theme emerged, some expressed in terms of having the ability to engage positively with doctors and other members of the oncology team, and for others it was seen as a skill of overcoming resistance from other professions that are caring for their clients.

“Understanding the NHS structure for cancer care locally and nationally.

Good working relationship with doctors, consultants and nurses.”

CP97

“I've only seen a handful of clients with breast cancer who wanted to optimise their nutrition. I don't consider myself 'experienced' in any way - but very keen to learn. The main area of knowledge I've had to call upon is to look beyond the accepted advice regarding cancer nutrition and to refer to the science regarding what might be helpful, and what might not be. I think one of the greatest skills, and one I'd like to develop, is to have the confidence in communications with oncologists and dieticians, as this can be a very difficult area. To date, they have all been utterly unwilling to discuss or communicate in any way and have dissuaded clients from continuing with recommendations”

CP115

“Extreme sensitivity/empathy

Willingness to work with spouse or whole family of patient

A very fine line between explaining which foods must definitely be eliminated (eg: sugar for all; milk/dairy especially for breast & other hormone-driven cancers) and not being too dogmatic or upsetting patient Not blatantly criticising patient's oncologist, yet discretely getting point across if I become aware that the medical consultant has giving misleading information re what foods to eat/not eat - or, as in some cases, consultant has given no dietary information at all, and patient asks me why”

CP226

When participants in the CP cohort were stratified according to their additional qualifications, their responses to the open question on skills could be further analysed, by counting categories identified by content analysis. This was to consider if practitioners' additional training influenced their

perspectives on skills for cancer practice. Technical and clinical skills and knowledge emerged strongly as important for working with people affected by cancer, equally for CPs with or without additional health and life science (HLS) qualifications. Similarly, the interpersonal skills of empathy, sensitivity and communication emerged as important for CPs regardless of additional training in coaching, counselling or psychotherapy. Therefore, for this cohort of NT practitioners, three clusters of skills and knowledge emerged as important; firstly technical/clinical emerged strongly, and interpersonal and inter-professional were also considered important,

Quantitative data and text from the survey describe how CPs acquired the skills they identified as important for cancer practice (Table 3). 86% (72/84) of the CP cohort provided this information. Respondents reported multiple routes for acquiring skills, and although 58% (42/72) of those responding acquired some during their original NT professional training, more commonly, self-directed learning was cited (79%, 57/72). Fourteen CPs reported that training in other healthcare disciplines had contributed to their practice skills, these respondents had qualifications in pharmacy (2), nursing (1), other health and life sciences (6), psychology, psychotherapy or counselling (2), other complementary therapies (2) and unspecified science (1). 15% (11/72) CP respondents noted that practice experience contributed to their skills.

Table 3. CP preliminary themes on acquiring skills for cancer practice

Acquiring skills for working with people affected by cancer (more than one response could be given)	(n=72)
Self-directed learning	57 (79%)
During original professional training in nutritional therapy	42 (58%)
Specific Continuing Professional Development (CPD)	26 (36%)
Additional post-qualification training	18 (25%)
Training in other healthcare discipline	14 (19%)
Working in a cancer centre	6 (8%)
Working with an integrative or CAM medical practitioner	3 (4%)
Experience	11 (15%)
Identified training courses and training resources	(n=45)
Training provided by named individual	19 (42%)
Training provided by cancer charities	12 (27%)
Training provided by NT training college	5 (11%)

4.3.1 Barriers to practice experienced by CP respondents

This section documents the first exploration of CP perspectives on barriers to working with people affected by cancer. When asked in the survey if they wanted more work with cancer clients, 43% (36/84) CPs indicated they did, 6% (5/84) did not and 26% were equivocal ('maybe': 22/84). A number of barriers to practice were identified, together with respondents' suggestions to overcome them are summarised in Table 4. Most frequently cited barriers were perceived opposition from, or lack of engagement with, mainstream cancer professionals, and secondly lack of practitioner experience, skills and confidence. Respondents identified that dialogue and engagement with mainstream healthcare professions, and improvements in NT skills and support may help to resolve barrier to NT practice with people affected by cancer. The main preliminary themes of barriers and respondents' suggestions to overcome them are reported below, with examples.

Table 4. Preliminary theme of barriers to cancer practice

Preliminary themes and categories
Barriers to cancer practice (n=57)
Opposition and lack of positive engagement with mainstream cancer professionals
Lack of practitioner experience and confidence
Lack of practitioner specialist knowledge
Restrictions on advertising and claims
Patient apathy or resistance
Lack of guidelines, protocols and standards
Cost of NT
Lack of evidence
Resolving barriers to cancer practice (n=49)
Dialogue, engagement and education of mainstream
NT CP specialised training and recognised status
NT cancer information resource
Practitioner support network

Experiencing barriers to practice was not universal, 7/57 CPs observed that no barrier to practice was evident for them.

“None - just my own time limitations”

CP15

“None. I get referrals from patients and doctors and specialist nurses”

CP97.

4.3.1.1 Barriers arising from dynamics between NT and other healthcare professions

In this section, CP perspectives are reported on the nature of barriers that appear to arise from the lack of engagement with, or perceived opposition from oncologists. For some, a barrier was due to differences in perspective

between NT and (some) mainstream oncology professionals, of the value of nutrition for cancer patients:

“The fact that they aren't advised by the NHS to make dietary changes because orthodox medicine do not recognise that there is a role for nutrition in cancer care.

Cancer patients lack trust due to their vulnerable state

Cancer patients just do not realise that there is extra support available.”

CP261

“Nutrition is not given relevance it deserves when supporting clients with cancer. Many cancer specialists, doctors and nurses seem to be ignorant to the importance of a good diet when a person is suffering from cancer, which is a huge barrier.”

CP186

Some CPs expressed strong feelings when discussing their perspectives in this area:

“The lack of knowledge from conventional doctors as these will stop any nutritional programme by use of fear. This is a huge barrier as when dealing with cancer because it is life threatening when conflicting ideas are proposed then the oncologist wins every time despite how we feel and know that this may be the wrong advice. This is heart breaking but one cannot interfere and must remain supportive.”

CP241

Other CPs emphasized that both sides of the perceived professional divide may be contributing to this barrier

..... it's important that we as NTs show people that we are not here to provide an alternative, but to complement what is already being given.”

CP247.

Some responses had ambiguous interpretations, elegantly demonstrating the shortcomings of survey as a tool for collecting data on complex concepts: for example this respondent's perceived barrier was succinct, but could be interpreted in a number of ways:

"the NHS"

CP67

4.3.1.2 Reducing barriers in inter-professional dynamics

To reduce these barriers, improving relationships and communication with other healthcare professions emerged as important. Informing and educating medical professionals about NT, providing evidence and improving professional recognition of NT practice and practitioners were proposed by CP respondents:

"Evidence-based trials with nutritional supplements; acceptance in the allopathic medical world that nutritional supplements can be beneficial.

Fund-raising task force targeting donor bodies? Identification of areas where research might be done and funding approved? Higher NT profile in traditional medical training facilities? Functional medicine training going mainstream? Advertising FM conferences in medical student journals? Offering free intro seminars on FM to trainee doctors (with procured funding) which introduces role of NTs?"

CP230

"More Education of conventional medical professionals how far nutritional therapy has come and how effective it can be. We need to show case studies and provide talks so that we are all supporting clients for the best possible outcome. Clients are often told that we offer false hope and not to waste their money on us"

CP241

“Better integration and working between health professionals to break down the barriers and improve communication”

CP147

Broadly, arrangements enabling collaboration with, or direct integration of NT into mainstream care were seen as ways forward, for example:

“By the NHS have NTs in hospitals”

CP71

“Have all cancer patients being monitored by NT's in hospitals and ensure that those patients when in hospital receiving treatment are given nourishing and wholesome food.”

CP39

However, for some CPs, there appeared little hope of overcoming these barriers arising from opposition from other healthcare professions:

“I do not think it will ever be resolved...”

CP33

Therefore, an emergent preliminary theme from the survey suggested barriers to practice were experienced by CPs in the dynamics between NT and mainstream healthcare professions. A number of potential ways to improve these relationships emerged which included better recognition of NT as a practice and as a profession.

4.3.1.3 Barriers associated with NT practitioner skills and knowledge

In this section, CP perspectives on gaps in their skills and knowledge as barriers to cancer practice are documented. Specific areas of knowledge and skills were identified:

“No special certification”

CP182

Lack of contact with medical staff and lack of consistent messages from health service about nutrition and medical treatment
Lack of resources e.g. recipes, general guidelines for different treatments”

CP46

“Confidence in communicating with medics and general knowledge and experience”

CP115

“Am nervous about getting things wrong & not being able to back up nutritional protocols with evidence. How to present a case to oncologists, etc”

CP135

“... - as I don't specialise, I find it hard to get to the level of knowledge and confidence that I feel I need in this area.”

CP21

As documented in section 4.3, the CP cohort identified three clusters of skills and knowledge they considered important for cancer practice: technical/clinical, interpersonal, and inter-professional. Respondents also reported that lack of training was a barrier, and suggested that specialist training was an improvement that may help to reduce this barrier.

“More advanced-level training
Support from fellow professionals”

CP103

4.3.1.4 Barriers associated with information resources available to CP

In addition to inter-professional barriers and gaps in NT skills and training, deficiencies in information resources emerged as barriers from the CP survey data. This section also presents data, from a series of survey questions that sought to address the broad question of how CPs access, assess and interpret evidence and other information in practice, as an important element of evidence-based healthcare. Data on three aspects are

presented here: firstly, specific areas of information need including difficult questions arising in practice, secondly, sources of information currently used and their perceived usefulness, and finally desired improvements in information resources.

Firstly, 52% (44/84) CP survey respondents reported the types of information they need in practice and where they source them, summarised in Table 5.

Table 5. Information needs and sources used by CP respondents

Preliminary themes and categories
Information needs (n=44)
Nutritional supplements
Cancer treatments: chemotherapy and radiotherapy, side effects
Drug-nutrient interactions
Cancer biology
Evidence for nutrition interventions
Diet
Psychological and emotional impact of cancer
Information sources consulted (n=44)
Pubmed/Medline or academic library
Other web searches
Drug interactions databases
Books
Cancer centres and cancer charities
Discussions with colleagues and professional discussion forum
Training course material
Professional association
Suppliers and pathology laboratories
Most difficult questions to answer in cancer practice (n=34)
Questions from clients – differences in nutrition advice received
Evidence for nutrition interventions
Advice for clients who choose not to have chemotherapy

CP respondents were asked to note difficult questions arising in practice, and 40% (34/84) provided information. Responses reflected firstly difficult questions that practitioners were asked by their cancer clients, and secondly questions the practitioner was seeking to answer that were not well addressed by research.

Difficult questions arising from clients appeared to have a common thread, of conflict or discrepancy between advice that clients may receive from their oncology team, and advice from the perspective of nutritional therapy. These examples suggest that some respondents and their clients may experience or perceive an apparent paradigmatic rift between 'mainstream healthcare' and nutritional therapy:

"I think the most difficult aspect is taking a balanced view when I have no medical experience. For example, if the scientific literature says X and the doctor/dietician says Y, then sometimes there is a good reason for this, and I lack the confidence to ask about this in case of a negative reaction. Clients are generally quite intimidated by their medical professional, and are unwilling to press for explanations in case they 'upset' them. I find this very frustrating as I strongly feel that we should all be involved in our own care and be fully informed so we can make the right decisions for us. I'm particularly confused about antioxidants as there is so much conflicting evidence. I also get a bit frustrated and sometimes feel that there is no point whatsoever in making any supplement recommendations as the medical professional will usually dismiss them out of hand, without giving any explanation apart from "you don't want to be bothered with that stuff!"

CP115

"Ones which you know will contradict advice given out by NHS sources. Especially surrounding a high sugar, high fat diet. NHS sources encourage maintaining body condition by eating a diet high in these food groups whereas I would tend to discourage. For example, one male, colon cancer patient recently was encouraged to regain weight by eating jelly babies and chocolate. I have been frequently

challenged on my view on this type of eating by NHS sources when I am working as part of xxx team. My answer is always to quote/show evidence based research to back up my beliefs."

CP72

"Sorting out the myths from the facts. Clients come with information given by health professionals inside and outside the NHS which are sometimes misleading and sometimes incorrect. Researching these to ensure information given is the most accurate and up to date takes time."

CP109

For some respondents, specific technical and clinical questions were noted as difficult to answer, as evidence may be lacking, difficult to find, or unclear:

*"Dairy and breast cancer
Soya and breast cancer
Other foods linked to breast cancer."*

CP7

"clinical studies on NT on cancer"

CP182

Questions on the use of nutritional supplements during cancer treatment also were noted as difficult to answer, with a common thread of concern for safety and interactions between treatments and supplements:

*"cancer-nutrient interactions
cancer-chemo/radio interactions
cancer-chemo/radio-nutrient interactions
cancer outcomes as statistics or case studies
psychological aspects of cancer diagnosis and survival"*

CP230

CP respondents also named sources used for specific information:

*"I need information on.....recipes for clients who have lost their appetite, sense of taste, can't swallow etc.
.....so I generally refer to Recca Katz's cookery book and Nourish by the Penny Brohn Centre and Christine Bailey."*

CP137

*"I need information on..... Up to date research
.....so I generally refer to the internet, RSM (Royal Society of Medicine) or library"*

CP71

*"I need information on..... Drug / Food interactions
.....so I generally refer to Natural standard database
I need information on..... Nutrient efficacy on cancer
.....so I generally refer to Pubmed"*

CP1

CP opinions on specific sources of information and how useful they felt they were to meet their needs were collected using Likert scales (Table 6). 79% CPs (66/84) provided responses. The rating offered was 1-5 where 1 is 'least useful' provided some indication of this subjective judgement. Literature searches of databases such as PubMed/Medline, which include peer-reviewed publications, were most highly rated for usefulness (mean score 4.02/5), whereas supplier information and unspecified web forums were rated least useful. Respondents rated the usefulness of some named information sources for information on cancer treatments and interactions between drugs and nutrients, rating named sources such as the British National Formulary above National Institute for Health and Care Excellence (NICE) guidelines or other professionals. Desired improvements in information resources identified by CPs are also listed in Table 6.

Table 6. Information sources used by NT practitioners working with people affected by cancer

Usefulness of information sources, Rating 1-5, where 1 = least useful			
	Mean (Standard Deviation)	Median	Mode
Information sources (n = 66 CP)			
Literature searches	4.02 (1.318)	4	5
Discussions with colleagues	3.59 (1.539)	4	5
Specific peer-reviewed journals	3.38 (1.778)	4	5
Continuing professional development	3.48 (1.395)	4	4
CAM magazines	3.14 (1.487)	4	4
Textbooks	3.21 (1.376)	3	3
Professional Associations	2.68 (1.303)	3	2,3
Supplier information	2.50 (1.327)	3	3
Other web forums	2.56 (1.550)	2.5	1
Information on cancer treatments and drug-nutrient interactions (n = 65)			
Medicines information sources	3.42 (1.457)	4	4
Other nutritional therapist	2.97 (1.531)	3	4
NHS/NICE guidelines	2.91 (1.422)	3	3
Other professional colleagues	2.80 (1.593)	3	4
Preliminary qualitative theme (n = 40)			
Desired improvements in information sources to support cancer practice:			
Specialist cancer NT training			
Access to research evidence, cancer NT database			
Reviews, guidelines and standards			
Education for patients and mainstream healthcare			
Discussion forum or conference			

4.3.2 Improvements in information resources for CPs

Access to evidence such as in specific journals or databases therefore appeared important to CP respondents. Other desirable improvements in information resources included access to specialist information, guidelines and documentation to use in clinical practice:

*“A regularly updated list of safe and unsafe supplements to use with cancer patients. Guidance on how to work with an oncologist
Guidance on how to manage expectations of cancer patients”*

CP261

“A specific cancer portal for nutritional therapy would be great, providing studies on efficacy, protocols, success stories, etc.”

CP1

“For those working independently, perhaps some guidelines indicating the specific issues that cancer clients face to ensure caution is used in recommendations of supplements etc. Oncologists have firm views about nutrition especially supplementation and will begin to recommend avoiding NT therapists if advice is given which persistently contradicts their views.”

CP109.

In summary, therefore, this CP cohort report that they access sources of peer-reviewed material, as part of the information they use in practice, and barriers to practice appear to include gaps in information available to them, including evidence resources. Specialist documentation such as practice guidelines and the ability to discuss with peers also emerged as desirable. This last facility of peer contact may have additional impact, as presented in the next section.

4.3.3 Barriers associated with practitioner experience and confidence

In this section, the preliminary theme of lack of practitioner confidence and experience as a barrier to practice is documented. In addition to specialist training and access to information resources, a preliminary theme emerged of CPs feeling needs for support, for sharing expertise and experience. Contact with other practitioners emerged as desirable through networking, supervision or mentoring:

“dedicated groups and regular meetings and sharing”

CP59

“A forum with access to an experienced practitioner for advice”

CP115

“Communication with other therapists working with cancer clients to share best practice.

A NT and cancer journal.”

CP7.

“...Working with/networking with national and local cancer support groups

Sharing case work or presentations within regional group meetings or NT supervision groups.

Specific forums for subject specialists within NT”

CP221

Maybe some sort of networking with other NTs working in this area?”

CP177

Therefore the need for peer engagement, in some form, to support each other and share best practice emerged as important for overcoming the barrier of lack of confidence and experience.

In summary, text data from the separate CP section of the survey provided some preliminary themes on specific skills and knowledge for practice, which included technical and clinical skills and knowledge, interpersonal skills to engage with the client, and inter-professional skills to engage with other healthcare professions. Text and quantitative data on how these skills and knowledge were acquired by CP respondents suggests that self-directed learning is widespread, and some have acquired skills from their professional NT training, on post-qualification courses, or from their training in other health or life science training. Preliminary themes of barriers to practice emerged in the dynamics between the NT profession and other healthcare professions involved in cancer care, and associated with gaps in practitioner skills, knowledge, information resources and in peer engagement and mutual support. Proposed improvements in these areas emerged from the CP data.

These preliminary themes served to frame the approach of the in-depth qualitative exploration, and are compared with preliminary themes from non-cancer practitioners, which will now be described.

4.4 Non-cancer practitioner perspectives on working with people affected by cancer.

In this section, data are reported from 165 survey respondents who self-identified as non-cancer practitioners (NCP), of whom 119 (72%) expressed interest in working with people affected by cancer. Preliminary themes emerging from text data, on NCP reasons for not working with people affected by cancer, included perceived and experienced barriers. Data collected from the NCP cohort also identified factors that may enable them to overcome barriers and start cancer practice should they wish to.

4.4.1 Perceived deterrents and barriers to working with people affected by cancer

This section documents the perspectives of NT practitioners on why they do not work with people affected by cancer.

Notably, the response rate to the first question for NCP was the lowest in the survey:

“If you are not currently working with cancer clients, you may wish to give reasons why”

22% (37/165) NCPs replied with reasons or commentary on not working with people affected by cancer. However, when NCPs were stratified according to whether they were actually interested in cancer practice or not, the response to this question differed markedly.

76% (31/41) of the ‘not interested’ NCPs gave a reason for their decision and/or identified deterrents or barriers. By comparison, only 5% (6/124) of NCPs who expressed interest in cancer practice or whose position on cancer practice was ambiguous, gave reasons why they were not working with people affected by cancer. However, perceived barriers were identified by some respondents in response to other questions in the NCP section, and some provided this data as a commentary at an earlier question asking respondents to define their status on cancer practice.

From content analysis of responses, and in comparing the preliminary themes with those emerging from the CP survey data, barriers could be grouped in three broad groups or domains. Firstly, factors emerged related to the nature of cancer practice, with a predominant thread of technical complexity and risk. Secondly, barriers were identified in the domain of the practitioner including training, confidence and experience. A third preliminary theme of perceived deterrents or barriers emerged as associated with the dynamics of inter-professional relationships in healthcare. (See Table 7).

Table 7. Non-cancer Practitioner (NCP) cohort preliminary themes

Theme and categories
Barriers preventing work with people affected by cancer (n=37)
Need for caution, perceived risks and complexity
Insufficient technical and/or clinical skills
Perceived or experienced opposition by doctors
Lack of confidence
Lack of experience
Support needed to start cancer practice (n=121)
Specialist training
Research evidence and information resources
Guidelines and protocols
Reducing resistance/ positive dialogue with doctors
Mentoring and building confidence
Emotional support

The perceived complexity and risk inherent in caring for people affected by cancer emerged as a predominant preliminary theme of barriers deterring practitioners from working with people affected by cancer.

“Complexity. Research for the efficacy if nutrition intervention is conflicting and seems like a minefield. Ethical issues are also complex.”

NCP154

“I feel that it can be a minefield with doctors and I am not confident enough to deal with this. Also although I understand and appreciate the benefits of diet in cancer, the reality of what cancer sufferers are able to eat during treatment and the effects of the chemo on nutrient levels etc and contraindications is beyond any training I have.”

NCP9.

"Im not sure I feel fully comfortable with the complexity of the disease and the evidence for the benefits of nutrition. I feel that nutrition is of course beneficial in general immunity and cancer prevention and prevenetion of reoccurance but Im not sure I have seen enough compelling evidence about the efficacy while a patient has the disease. I would be happy to take on a cancer client but on the understanding I was not trying to help them with the cancer but just their overall immunity and general health. To be quite frank I am a little scared to take on patients with such complex needs especially those undergoing chemotherapy as I dont feel we had sufficient training in college to deal with this and I definetly would not want to recommend supplements for fear that there may be unknown interactions that may occur. Im also a little concerned to work with these clients as I feel the conventional medical world are sceptical of the benefits NT can bring and I fear being challenged by them for anything I am suggesting to the patient. Obviously I wouldnt suggest anythign that couldnt be back up but is the evidence strong enough?"

NCP266.

For some respondents their caution was reinforced by advice during training that working with people affected by cancer was an area to avoid or be very cautious with:

"Noone other than family and friends have approached me, plus during training we were advised to be cautious when working with cancer clients . I would consider it on a pro bono basis and have volunteered to work witha support charity. As they were based in (location) I am in (other location) they already had a supportive NT in place."

NCP10.

Notably, some NCPs felt that there should be limitations on NT practitioners working with people affected by cancer, including respondents with other healthcare training:

“Ethically difficult as they have their own GP and oncologists, many of whom do not embrace nutritional medicine; I don't like charging patients, and treating those with cancer opens up the possibility of 'quack' claims that I prefer to avoid. I point patients seeking information/help towards Penny Brohn Cancer Care.”

NCP144.

“I do not believe Nutritional Therapy gives robust scientific training to support cancer care and would strongly discourage cancer support (while chemo) taking place unless in a medical NHS integrated team. I have both BANT and Registered Nutritionist status. As a registered nutritionist with 4 year degree and an MSc from xxx I am still not professionally entitled to support patients with cancer. Which I think is entirely right. It is an extremely specialised area and I don't believe non-medical practitioners should offer treatment which potentially conflicts with a patients medical care. For a number of years I was director of the nutrition clinic at xxx and we did not treat any patients who were actively engaged in cancer medication or chemotherapy or radiotherapy as a company policy.”

NCP108.

“I did work within an Oncology clinic for 1 year, and this actually heightened the fact that the clinical environment should really be not only multidisciplinary but also be overseen by a conventionally trained practitioner, which this clinic was.

Cancer involves so many different levels than just nutrition and I feel if someone wanted to specialise in cancer, then they need to be aware of mind support as well as body/systems etc.”

NCP102..

Emotional aspects of working with people affected by cancer also emerged as a preliminary theme in barriers which had deterred some respondents:

“Not an area that I wish to be involved in, find it emotionally very demanding and wary of the law.”

NCP181.

Aside from considering emotional aspects as a barrier, asking these questions within the survey may have led to some emotional reflection:

“On a very personal level, my sister's husband died of brain cancer and I find it too emotionally difficult to get directly involved with supporting cancer patients. On a professional level, please see previous answer - I am supporting the writing up of clinical case studies & will be supporting clinical trials into the potential use of the ketogenic diet as an adjunct therapy for brain cancer, but this is through collaborative working with a Dietician & funding via my brain cancer charity.”

NCP206.

“I myself have recently diagnosed with breast cancer, which means I already have relevant experience in an area I would have previously not chosen to support. This has focused my attention on cancer prevention, as 1 in 8 people will get cancer everyone we deal with has a potential to get cancer and therefore we should all be trained/do CPD in this area.”

NCP47.

Some NCP respondents simply noted they had other areas of interest they were pursuing, for example fertility and mental health.

4.4.2 NCP perspectives on reducing barriers to working with people affected by cancer

For those NCP respondents interested in starting to work with people affected by cancer, preliminary themes emerging from their data suggested desirable support resources. These improvements reflected the complexity of cancer practice, practitioner skills and knowledge, resources and support of the practitioner, and improved inter-professional relationships in healthcare.

Firstly, specialist training to enable the practitioner to work within the complexity of cancer practice, emerged as a predominant theme:

“There should be a specialised qualification that’s regulated or endorsed by the medical professional that combines chemotherapy/radiation and any other drugs and contra indications into supplements. Cancer is multi factorial number of diseases that’s under the name of Cancer (a proliferation of cells that create a tumor and become invasive). My question is that we need to work closely with the medical profession to understand their work which would enable us to compliment the patients treatment. I know chemotherapy is not always successful and there are so many factors for this - and that’s when ptatients may seek an alteranative therapist. Expectations need to be set too and there’s not much evidence to assure them.”

NCP188.

“I would like to undertake a specific course that is geared towards working with cancer clients and that is an accredited and recognised qualification”

NCP13.

“Training or approved online resource covering optimum timescales/periods of waiting for supplement use around radio- and chemotherapy. Specific cancer-drug/herb/nutrient interactions resource would also be helpful.”

NCP98.

Within this preliminary theme of training, in addition to training in technical and clinical skills and knowledge, a desire for skills to deal with legal framework of cancer care and the psychological aspects of cancer practice, and training in how to engage with oncology teams also emerged:

“before becoming an NT, I was involved in cancer and nutrition research (PhD was on prostate cancer and diet). I am therefore very interested to use this knowledge to help advise cancer patients on diet, I know from experience just how little they get from the NHS and how much they would like it (even just general healthy eating advice). However, I am worried about how to deal with the Cancer Act etc, and also that I have no experience in cancer counselling. I would therefore very much like to attend a training course or find resources that would help me with this.”

NCP65.

*“I would like training in these areas:
how to approach the patients medical cancer care team with my NT recommendations
specific training in how NT interacts with chemo and radiotherapy”*

NCP268..

Specific resources and tools for the practitioner also emerged as enabling working with people affected by cancer, notably access to research, guidelines and protocols:

“Guidelines that need to be adhered to with regard to treating cancer patients.

Training particularly in line with looking at case examples and successes.”

NCP243.

“Clear protocols and access to more experienced practitioner support.”

NCP214.

“1. Disclaimer text

2. Web text agreed with the ASA etc., that means that I can support clients without risk of a public drumming

3. Training - it was covered in my course at ION with one lecture - not enough, and anyway I haven't used it since and would need refreshing.

4. Guidance of reference literature.

5. Does the NMCD (Natural Medicines Comprehensive Database) cover chemo?

6. A link to a MD who can provide info on different kinds of cancer/NHS treatments etc..

7. Counselling training for me and subsequent support”

NCP132.

Furthermore, in common with CP respondents, NCP participants identified a need to develop professional networking, mentorship and/or supervision to support working with people affected by cancer.

An active support group - additional training module that NTs need to complete to qualify them to work with cancer clients

NCP260.

Within these preliminary themes appears a clear thread of seeking collaboration and complementarity to mainstream cancer care, which also relates to overcoming the barriers in the dynamics of inter-professional relationships

“Cooperative oncologists are needed as well as: - a clear scope of practice for NT working with cancer - useful evidence based resources specific for NT's - support of professional body - practice & ethics

guidelines specific to oncology patients whether they are in remission or dying etc.”

NCP154.

In contrast to the strong trend amongst NCP for interest in working in a complementary manner, there was a minor interest in ‘alternative’ approaches to cancer care

“Would like to see numerous case studies, the protocols, and client feedback / outcomes. Would members be prepared to share - subject to confidentiality and anonymity. Would not just want the success stories either.

The various alternative therapies, plant derived anti cancer substances/food, with evidence

Dove Clinic Bristol Cancer clinic and what they offer, and what results they have.”

NCP148.

Finally, the relevance of this research for practitioners was commented on

“It's nice that you chose to undertake this research.”

NCP78.

“..... thanks for working on the issue!”

NCP208.

“Great idea for a research project - I wish you luck!”

NCP206.

In summary, preliminary themes have emerged from text data from the NCP section of the survey on barriers that may have deterred some practitioners from working with people affected by cancer, potential means to overcome them, and additional resources that may be helpful for those starting cancer practice. These barriers relate to the complex nature of cancer, to practitioner skills, knowledge and disposition, and to the dynamics of inter-

professional relationships in healthcare. Amongst the preliminary themes of barriers and deterrents to cancer practice, some opposition was expressed to nutritional therapy practitioners working with people affected by cancer, by NCP with training in other health and life sciences including nutrition.

Preliminary themes of enabling factors emerging from the data relate to these specific barriers and include specialist training, guidelines for practice and specific support for collaborating with oncology professionals, to deliver NT in a complementary manner. These preliminary themes have provided a comparison with preliminary themes from CP participants, and have informed the in-depth qualitative phase using interviews with individuals and a group.

Chapter 5. Findings of interviews with NT practitioners who work with people affected by cancer

5.1 Overview

In this chapter, the first set of findings of phase 2 of the research project are reported.

This qualitative phase explored cancer practitioners' perspectives and their needs for future professional development in this area, through collecting and critically analysing qualitative data from interviews. Complementing this, reported in Chapter 6, critical analysis of data collected in interviews with non-cancer practitioners explored their reasons for not working with people affected by cancer, and the resources they perceive could enable them to, should they wish to enter this area of practice. Perspectives explored with both CP and NCP cohorts were informed by the Phase 1 survey data and encompassed rewards and motivation, barriers and challenges experienced in practice, and particularly how these barriers might be overcome. One specific aspect of professional development emerging from the interviews and the survey, the use of practice guidelines, was explored in a group interview with a consensus panel composed of a committee of a professional association, as reported in Chapter 6. All interviews were professionally transcribed anonymously and then analysed using the Framework method. Professional development needs were identified within CP and NCP participant narratives that can be used to inform the development of safe, evidence-informed NT practice with people affected by cancer, reported in Chapter 7.

A summary of characteristics of CP participants is presented in Table 8 along with NCP participants for comparison. Thirteen NT practitioners (12 female) who self-identified as cancer practitioner (CP), described in sections 5.2 were interviewed. The analytical framework that was developed for the CP narratives is summarised in Table 9. Themes are grouped within topics.

Notable professional characteristics of the CP cohort are first outlined, and participants' motivation to work with people affected by cancer are described, to provide context for the major themes of barriers and challenges, which are then reported.

In this first analysis of NT practitioner perspectives on cancer practice, three major themes emerged from CP narratives that have potential implications for the NT profession and for people affected by cancer. These are summarised in Table 10 and described in section 5.4 and subsections. Firstly a major theme in the interview data, that was not clearly evident in the data from the Phase 1 survey, was the psychological and emotional impact of working with people affected by cancer. Notably, stress or difficulty was associated with this aspect of practice. Secondly, concurring with the phase 1 survey data, specialist training provision was felt to be inadequate and participants identified desirable improvements. Thirdly, also reflecting the survey data, dynamics and engagement between NT and other healthcare professions were considered problematic, and were perceived to impair the professional service NT practitioners could provide.

Table 8. Participant characteristics of Cancer Practitioners (CP) and Non-cancer practitioner (NCP) cohorts

Participant characteristic	CP n=13	NCP n=8
Gender		
Female	12	8
Male	1	
Years in NT Practice		
10 or more years	8	1
5 - 9 years	3	2
Less than 5 years	2	5
NT qualification		
Higher education diploma	6	5
Bachelor's Degree	4	2
Post-graduate diploma or degree	3	1

Additional higher education qualifications*		
Health and life sciences	6	2
Business	0	3
Psychology and counselling	2	0
Exercise, yoga, pilates	2	1
Food science & technology	1	0
Maths, physics, chemistry, engineering	1	1
Social sciences and education	1	0
Arts, humanities	0	1
CAM – other therapies	1	0
None noted	1	0
Geographical region		
South east England	7	6
North east England	2	0
North west England	2	0
Central London	1	0
Eastern England	1	0
Scotland	0	1
Wales	0	1
Practice setting*		
Mainly sole practitioner	7	3
Mixed, including sole practice	4	5
Team practice	2	0
Additional health modalities practiced*		
Exercise, yoga, pilates teaching	2	1
Coaching, counselling, psychotherapy	2	0
Massage and manual lymphatic drainage	1	0
Pharmacy	0	1
Nursing (actively registered and practicing)	1	0
CP self-defined extent of cancer practice		
Mixed caseload	10	
Predominantly cancer clients	2	
Cancer specialist	1	

NCP self-defined interest in cancer practice		
Active attempts to work with cancer clients		3
Does not see people affected by cancer		3
Supported friend or family member with cancer		2
*Participants may report more than one		

Table 9. Analytical Framework developed for CP Narratives

Practitioner and practice characteristics	
Themes	Main categories emerging
Practice setting	Sole practitioner Multidisciplinary clinic Cancer centre Private medical facility Health & wellbeing / fitness centre, retreat Geographically remote
Practice workload	Full time NT practice Part time NT practice Combines individual client work with other NT work
Clinical interest	Mixed client case load Specialising in clients affected by cancer Clients with complex chronic ill-health Adults clients Paediatric clients Multidisciplinary practitioner Community nutrition workshops
Cancer practice themes	
Themes	Main categories emerging
Cancer practice paradigm	Complementary, supporting through treatment Cautious approach with patients in cancer treatment Holistic approach, beyond physical needs of clients Patient empowerment by supporting self-care with diet

	<p>Individualised care</p> <p>Detailed history taking important</p> <p>Analytical approach</p> <p>Thinks about cancer biology</p> <p>Focuses on digestive system</p> <p>Focuses on immune system</p> <p>Guided by nutrition tests</p>
Clinical advice and resources used with clients	<p>Dietary advice, handouts</p> <p>Stress and exercise advice</p> <p>Symptom alleviation advice</p> <p>Support/signposting for client mental health</p> <p>Suggested books for clients</p> <p>Involves family in appointments</p> <p>Advises on supplements</p>
Motivation and reward themes	
Themes	Main categories emerging
Motivation to start working with people affected by cancer	<p>Personal cancer journey</p> <p>Witnessing cancer in close friend or family member</p> <p>Cancer practice in another discipline</p> <p>Inspiration from cancer survivors</p> <p>Identified need</p>
Rewards in working with people affected by cancer	<p>Giving back</p> <p>Empowering patients/clients to self-care</p> <p>Technically varied</p> <p>Privilege to help cancer patients</p>

Information themes	
Themes	Main categories emerging
Information resources used in practice	Peer-reviewed literature searches Medical websites for professionals and patients Internet searches Textbooks Drug information databases Drug-nutrient interaction databases Other NT practitioners
Improvements needed	Cancer NT evidence database Guidelines and protocols CPs sharing expertise Access to full publications
Information resources	
Professional connections	Formal professional networks Other NT practitioners Cancer charities Communication with mainstream healthcareers
Skills and training themes	
Themes	Main categories emerging
Important skills for cancer practice	Clinical consultation skills Understanding complexity Criticality and open-mindedness Finding and appraising evidence Recognising risks of NT practice Understanding patient and family perspective Psychological and coaching skills Bioscience and clinical cancer knowledge Skills in communication with oncology team Recognising need to keep skills up to date
Sources of skills and training for cancer practice	During initial NT training Other healthcare practice or training Self-directed learning Seminars and workshops

	Post-graduate course Own cancer journey Witnessing cancer journey in close friend or family Textbooks Working with cancer expert
Training improvements	Psychological and emotional issues In-depth knowledge of cancer Critically reviewing research Patient perspective Clinical assessment and diagnostic skills
Delivery of training improvements	Conferences, seminars and workshops On-line or distance learning modes Shadowing / observing oncologists Training alongside other healthcare professions Speaker and training provider important Textbooks High academic entry requirement Training location and availability important

Challenges and barriers themes

Themes	Main categories emerging
Challenges and barriers to practice	Medical opposition Conflicting nutrition information from other professions Lack of communication Patient acts as intermediary with oncologist Isolation Patient expectation Patient attitude Skills and knowledge Information and evidence Inter-professional relationships Workload and time management Early career advice Restrictions on publicity

Improvements to overcome challenges and barriers to practice	Professional recognition Professional networking Supervision, mentoring Inter-professional communication
Perspectives on impact of this research	Valuable research Outcome benefits profession Participation encouraged CP to reflect on practice

5.2 Characteristics of the cohort of cancer practitioners

The gender, training backgrounds of these 13 CP participants, including gender and level of NT training, were reflective of the range reported in the survey. Six had additional life science or healthcare qualifications including biochemistry (1), pharmacy (1), nursing (2), or post-graduate nutrition degrees other than NT (2). One chemistry graduate and a food technologist were also in this CP cohort, and two had additional psychology-based training. Geographic distribution indicated that most were in London and the south east. There were no volunteers from Scotland, Wales or Northern Ireland in the CP cohort, therefore although the study aimed to encompass the whole of the UK, the CP participants were all located in England.

5.3 Practice settings and workload of CP participants

In this section, the practice arrangements of CP participants are described, providing context for their perspectives on cancer practice. All participants worked at least some of the time as sole practitioners, which could include working from home, in single offices or shared locations with other professionals such as osteopaths, acupuncture practitioners and counsellors. Some described working at several locations each week, or combining NT practice with other healthcare practice or with teaching NT. Individual client work emerged as a common work pattern, but also working in health settings where clients can access different complementary therapies. Five

participants described working with groups of clients in cancer centres or health workshops.

Lone working, even in a multidisciplinary practice, was described by some participants as lonely or isolated. The impact of lone working and isolation will be explored in further detail in section 5.5.

Having a separate office from home was seen, however, to have some advantage, even if isolating:

“I took on an office, which is a single office in a little office building... there’s no other complementary practitioners here, so I am a little bit isolated. But I enjoy being here because it allows me to leave the house in the morning, shut the door and go to work, because otherwise I get too distracted at home. ”

Participant CP379

Participants outlined their practice caseload and general approach, with some describing aspects of practice they felt were important. Overall there was a predominance of mixed clinical practice, with clients affected by cancer as well as those with other health concerns.

“I did do seven years after I graduated with my BSc. I did a Masters in Obesity and Weight Management because I found that there were so many different conditions that were helped by getting people to lose weight. ... even after I finished the Masters, I didn’t want it to be the main focus of my practice because I rather enjoy the challenge of lots of different conditions. I don’t, I certainly don’t just focus on cancer but I don’t shy away from any opportunity to see a cancer patient at any stage or any type of cancer.”

Participant CP372.

Participants varied from experience with a few cancer clients to one participant working exclusively with people affected by cancer. The duration of experience with clients whose main health concern was cancer varied from a few months to 15 years. Some participants emphasized their practice paradigm was a complementary role of NT for people having treatment for cancer, of helping to sustain and support recovery during and after cancer treatment.

“So I think a lot with cancer treatment things are being done to you and you get lots of different appointments and procedures and medication and things like that, whereas actually your diet is something that you can, you're in control of. And I think if people like well, a) if they want advice in terms of being healthy and looking at their diet in that way then often people can feel, well I doing something myself to help myself. But also I would also (have) people who had specific symptoms. So people who had come through treatment and it left them feeling very tired or going through treatments like chemotherapy where your appetite changes and also the foods, and your tastes change so things that you used to love you don't, hate now and things like that.”

Participant CP377.

“I don't work with cancer patients while they are having active treatment, it's often post treatment where I can help rebuild the body a bit, and so they're feeling often very poorly and very much like their bodies have been taken over by medicine and procedures and medical people.”

Participant CP375.

In summary, CP participants worked alone at least some of the time, most saw clients with a range of health concerns including cancer, the level of practice experience and other qualifications varied, many had other life

science or healthcare training. A theme of providing nutrition advice complementary to cancer treatment also emerged.

5.4 Motivation and rewards in working with people affected by cancer

In this section, to further contextualise the main themes in their perspectives, participants' interest and motivation to work with people affected by cancer are reported. Initial motivation to start cancer practice was explored, then the rewards and motivating factors that sustain their practice. Three factors emerged as influencing participants initially to start working with people affected by cancer. Firstly, witnessing or personally experiencing cancer, secondly being inspired by an early career encounter with highly motivated cancer patients and survivors, and thirdly, to a lesser extent, working with cancer patients in another healthcare role.

Experiencing or witnessing a cancer journey emerged strongly as an initial motivational factor. Four CP participants reported their own cancer journey had been a factor, of whom two changed their career to NT, and two already in the profession started working with people affected by cancer. Four further CPs had been motivated by witnessing a cancer journey of a family member or close friend, and seeing a need for nutrition advice.

"I had cancer 12 years ago so it's the whole reason I am where I am. ...and even when you've been through it you're bloody terrified about it happening again, and what better insurance policy to have, than feeling like you're doing everything you can to make your body as healthy as you can."

Participant CP378.

"... in fact, I came to nutritional therapy for very personal reasons to do with cancer because there were three people very, very close to me who had cancer, one of whom had just died before I started my course, and the other two were undergoing treatment and, either, I think it was during, while they were still at university, died and I just knew that there

was something more that could be done and so, anyway, that was, I suppose, almost naivety and idealism that led me to do this, although the other main reason is that I've always been passionate about food and the amazing effects that different foods can have, amazingly bad or amazingly good..."

Participant CP372.

Secondly, for some CPs, a positive experience early in their career with groups of cancer patients and survivors, motivated and inspired them to develop their practice in this area:

"I got asked to go and do a talk for a cancer support group, ...and just quickly realised that people with cancer were very motivated and that really drew me to that group of people because I knew that they were really, really open to making changes to their diet and lifestyle and were very motivated, engaged and often, not always, but often really embraced what I was saying and were ready to go for it. So I liked that about it but also it's such an interesting area because it's so vast. There's so many different types of cancer. It's fast moving in terms of the research so there's always masses to learn so I just found that I was really interested and enjoyed working with that group of people and so I just continued really and just decided that I'd make that my specialist area and it, 15 years ago there weren't many nutritional therapists working with people with cancer, so ...it was an area where support was, people were really...Crying out for it."

Participant CP382.

Thirdly, for two CPs, working with people affected by cancer in other healthcare roles led to a developing interest in NT as a practice:

“Yes so I started in physical therapies so I was doing neuromuscular massage and manual lymphatic drainage. Where I really came across my cancer patients first actually was doing manual lymphatic drainage. Anyway, so doing various remedial work, physical body work. Then I qualified as a psychotherapist and so started that practice where I was specialising in, and still do actually, eating disorders. And then I got my nutritional medicine degree, and I sort of combine it all in different ways, all the disciplines merge into one at times, all training, but my main focus and my main areas of research and personal reading and study and continual professional development are all in nutritional therapy.”

Participant CP375.

Beyond the initial interest and motivation to start working with people affected by cancer, a number of sub-themes emerged in exploring the theme of motivation and rewards experienced in established practice. A common thread was the reward experienced in empowering and supporting people affected by cancer, expressed by eight participants, enabling clients to help themselves and have a sense of some control of their health during their cancer treatments.

“I think that the biggest reward is that they then become empowered which is the way it should be because most people having chemotherapy or radiotherapy seem to hand themselves over and relinquish responsibility for themselves and I think that through nutritional therapy, people can gain back their identity and feel more positive about their outcome.”

Participant CP384.

For some a sense of feeling privileged to work with people through their cancer journey:

“I find working with people who are up against the biggest challenges in their life and questioning their own mortality, I find it a real privilege to be working with people in those sorts of situations and I find that

watching people face those situations and how they deal with it and sometimes the transformation that's available to people when they are in such a difficult situation, I think that that can be quite amazing so that's another benefit....

Participant CP382.

For a CP who had a personal journey with cancer, the reward of empowering and supporting seemed more poignant where the client's journey resonates with their own:

"...there's the personal karma, giving something back, sharing, I think sharing your life experiences and helping people who are going through what was to you the worst experience of your life. I've got a, I've got a client at the moment who is in almost exactly the same situation as me, except, as I was back then, except she's been told that she's incurable, but she's got a little girl who's her absolute life, my daughter just, I often say to her, you're what got me through it. But this, you know helping this woman cope when her, actually the other people around her aren't being that supportive is, it just, I find that hugely rewarding, so that's, there aren't really words for that."

Participant CP387.

In summary, CPs had been initially motivated by their own cancer journey or witnessing that of a close person, or by experiencing the motivation of people affected by cancer, or providing cancer care in a different role. Motivation to sustain their interest in cancer practice lay in the rewards of empowering cancer patients to self-care with nutrition, or for some, a sense of 'giving back' for their own survival through cancer. After exploring motivation and rewards, participants explored challenges and barriers to practice and

desired improvements, which will now be described. These identify areas for potential professional development.

5.5 Challenges and barriers to working with people affected by cancer

In this section, barriers and challenges NT practitioners experience in working with people affected by cancer are reported for the first time. A number of themes emerged, from which the major themes are derived, as summarised in Table 10.

Table 10. Summary of major themes and sub-themes emerging from CP interview data

Major themes	Sub-themes
1. Emotional and psychological impacts of working with people affected by cancer	Client expectations of NT Grief after death of clients working alone Lack of training to manage impact
2. Specialist training	Current provision inadequate Skills to manage emotional and psychological impact needed Lack of recognition problematic
3. Relationships between NT and oncology professionals	NT practitioners seek collaboration Conflict and opposition perceived Client may feel conflicted

5.5.1 MAJOR THEME 1 – emotional and psychological aspects of working with people affected by cancer.

In overview, a strong theme emerged clearly of the challenges of the emotional and psychological dimensions of working with this client group. The majority of CP participants described these difficulties, particularly dealing with people with a poor prognosis where treatments have failed to control their disease, and there were unrealistic expectations of nutritional therapy to 'treat' or 'cure' cancer:

But it comes with massive challenges because, well, across the board with my therapeutic work, people want you to fix them and we never claim, well I certainly never claim to be able to fix people but they want you to be able to do that, understandably, and so you have to manage people's expectations really carefully and for my emotional, psychological well being not take on the burden of all the patients I see who come to me hoping I'm going to fix them, which can be really tough.

Participant CP375.

"So there are some people I've had who have had terminal cancer, and the most awful thing about dealing with those people is trying to manage their expectations. And explaining to them that what we're doing is trying to help them have a better quality of life in the time that they've got but that I, I'm not setting myself out to be able to cure them of their terminal cancer. And I remember I did have one case particularly that was particularly difficult in this respect when there was someone in her 40s who had ovarian cancer, terminal ovarian cancer, and we'd had quite a few appointments and she was eating a lot better etc etc, and she was feeling better, and then she went very badly downhill and instead of coming to see me for that appointment, her partner came in and her partner was saying to me, what are the, what is your understanding of what you can do here, she asked some very direct questions. And I said to her, look all along I've been

saying to X we're trying to make it easier for you, we're trying to improve your quality of life, we're trying to help with some of the side effects of the medications, but I can't cure your cancer. And that really made me realise that actually perhaps I hadn't been strong enough in saying that to the actual patient because the person I spoke to, her partner, then said to me, yes, that's what I thought it would be the case but she's not, she doesn't understand that. And that really brought it home to me. I mean, I thought I had been saying that, but I think people when they're in that position sometimes hear what they want to hear, and that was horrible. That was just a horrible, horrible situation."

Participant CP380.

Analysing this major theme of emotional and psychological impact of cancer practice, four related sub-themes emerged. Firstly, practitioners feel challenged by the pressure of high expectations from patients, secondly, their clients may succumb to their disease which may lead to grief experienced by practitioner. Thirdly, they often work alone and are less able to discuss and be supporting with their feelings appropriately, and underpinning these was the fourth sub-theme of lack of skills and preparation to deal with these aspects of their practice. Some participants see these as an inevitable challenge that they try to manage, and for one participant it had become a deterrent to seeing further cancer clients and he was therefore refocussing on a different clinical area:

"...So that's where my focus is going now, although, as I said, I do still give lectures on cancer and nutrition to xxx, (college name). I still have an interest, but I did find it a struggle, I'll lead into those answers later on about being alone with it and dealing with the grief..."

...The family were so nice, they were really supportive and thanked me for everything I did, but I don't know whether I got too involved or not. It's difficult to know, the grief I suffered from, I think I must have got too involved."

Participant CP370.

Isolation as a result of the frequent pattern of work as sole practitioners was a strong thread through this theme.

"I do work on my own. I'm in a clinic that's multidisciplinary but I'm the only nutritional therapist. It's very solitary, it really is."

Participant CP372.

"I hate working as a sole practitioner. I love the role, don't get me wrong at all, but I wouldn't do any more than two days in clinical practice, even though I'm seeing people all day because most people out there, your own family don't get what you're doing....And so I can't come home and say to them, oh, I've done this today or this has been really good or I'd just love someone to just talk this through with me, because they just wouldn't get it."

Participant CP395. **(This narrative was also in relation to other complex areas of clinical work)**

"So there was an older female client... I just had a gut feel that it wasn't going to be good news. And I'm surprised just how, I don't know, how affected I was. And I worry, well the nature of nutritional therapy is such that you do build these, a rapport and friendships with your clients and so any, it's difficult to keep that professional boundary and protect your own vulnerability I think... as a nutritional therapist, unless you're working in a multi-disciplinary team, which seems very rare, that support network isn't really there."

Participant CP385.

“but sometimes actually thinking about what would be nice for me is to have somebody I can call and say this is what’s happened to me today.”

Participant CP383.

The predominant perspective was that these challenges bear heavily on cancer practitioners, and skills in managing the emotional and psychological aspects of practice emerged strongly as desirable. In contrast, two participants, both in cancer practice for more than 10 years, offered different perspectives: one felt there was an intrinsic reward in dealing with the emotional aspects of the work and that it was not burdensome. The other recounted that although her work was solitary, she managed these challenges, had received helpful training and was aided by an informal network of supportive peers:

“...I just have to be, remain very, very professional and don’t allow my emotions to get engaged at all because I don’t think I could really give professional advice if I was getting emotional or whatever... have some sort of an inner voice that talks to me and enables me to keep on track with the professionalism...”

In fact, in the 13 odd years since we graduated, there’s a group of us, more than 6, 8, who have stayed and become even closer friends...And we turn to each other for everything, everything...I don’t know how I would ever have got to where I am without those women. They are all women. They’ve been amazing”.

Participant CP372.

Therefore, in this major theme, of emotional and psychological impact of practice with people affected by cancer, participants’ perspectives highlighted aspects of practice that are previously unreported, and identify areas of professional development need.

5.5.2 MAJOR THEME 2 – cancer practice needs specialist training and resources

In overview, the second major theme emerging from the interview data was that challenges and barriers to practice arise in the skills and resources available to practitioners. Notably, specialist training was poorly provisioned, including technical skills and particularly skills for dealing with the emotional and psychological impact of practice, this connects with the first major theme as reported in 5.5.1.

Some participants recalled being advised during their initial professional training to avoid working with people affected by cancer, and there was emphasis that training provision was inadequate for this work. Potential improvements emerged in training and in the information resourcing and support arrangements.

(Interviewer: thinking about nutritional therapy training, how do you feel that the training you have had to date has actually prepared for the work that you do?)

“Appallingly. In both the scientific, the data and the practice, the practical practice of working with cancer patients, none of my training has dealt with that specifically. I have pursued some specific training to do with cancer but that was off my own volition because of my interest in it. And certainly in none of my training in nutritional medicine was there any ever mention of dealing with the person's emotional needs and psychological needs, I guess there's no scope for it because there's so much to cover in the science of the nutrition but I do think that's hugely important across the board with nutritional therapy that we have tools to cope with that as well.”

Participant CP375.

“So very little training actually. I suppose I got most of my initial cancer care knowledge from my MSc, which I did with xxxx, and I did a module on cancer care, and that’s when I really started thinking about how I could help. But in my original nutritional therapy diploma obviously there wasn’t really anything and I suppose it’s an area where there are few CPD opportunities.”

Participant CP380.

Compounding the reported deficiencies in training, some participants cited barriers related to lack of resources, with contradictory or incomplete evidence on cancer nutrition, and absence of formal practice guidelines as challenges and barriers. Disparity between NT practitioners’ view of appropriate nutrition and the advice given by oncologists emerged as barriers. This was exemplified by the variable and apparently contradictory advice received by patients from their oncology teams on eating live yoghurt during chemotherapy. This will be considered further in section 5.5.3 as an aspect of inter-professional dynamics.

“I think one of the frustrations for me is the lack of guidance about what I can do... I would always err on the side of caution but I think it was a frustration that it felt too cautious at times,...and also to be honest the varying degrees of advice and support and the contradictory nature of that advice for people. It was quite frustrating at times so you’d get some consultants who would say, oh yeah probiotic yoghurt’s fine, no problem with that. Other ones would say, no, and it didn’t seem to be that either from our point of view, a nutritional therapist’s point of view or even from a medical point of view that there was any clear advice where you could say,...and because there is a lack of clear evidence you always have to try and err on the side of caution. So I think that was the most frustrating thing I think.”

Participant CP377.

In contrast, one participant noted the challenge was more in having the skills to locate and apply appropriate information in practice.

“So knowing how to, first of all, find the research, then appraise it properly, etc, I think I’ve learnt that through other ways not through my nutritional training. I think there is something that’s important about the training that practitioners get on that side...And then in terms of access, well, that’s difficult. Unless the colleges will pay for library access then people have to pay for them themselves which obviously is very limiting for a lot of people”

Participant CP382.

Therefore, in this major theme, lack of specialist training and resources, such as support to access and interpret evidence, presented challenges and barriers to practice with people affected by cancer. From this theme, documented for the first time, professional development needs have emerged.

5.5.3 MAJOR THEME 3 – dynamics between healthcare professionals working with people affected by cancer

In this final major theme for CPs, challenges and barriers to practice emerged from the dynamics between the NT profession and other healthcare professions. Participants discussed that these deserved to be improved in order to improve the service that NT practitioners can provide for people affected by cancer. In overview: narratives of contradiction, conflict, opposition and lack of engagement predominated.

“Yeah, well, the main thing that comes to mind is the attitudes of health professionals. That, I find, is a big barrier”

Participant CP382.

A sense of frustration was expressed by several participants. Some described contradiction or disparity between the nutrition advice given by NTs and the nutrition paradigm of other healthcare professionals, who appeared to place a very different emphasis on the value of nutrition for people affected by cancer. Some participants described their clients being advised by other healthcare practitioners that diet has no impact on cancer, or that the advice from NT practitioners could have an adverse impact on health. This was particularly evident in the narratives from participants who had all had personal experience of cancer and undergone cancer treatment:

“Oh, the very negative response from the hospital doctors and some degree of incredulity talking to the nurses while I had treatment about how I’d changed my diet. They didn’t get it...”

Participant CP384

“One of my big questions is, should oncologists give dietary advice and I suppose I don’t think they should. To give you an absolute example, one of my friends has an astrocytoma. She’s a medical doctor, and she wrote a 16 page research paper for her oncologist to look at some of the options on, she’s actually pro drugs, so she looks at stuff like statins, and all that that we’re not so keen on, but she looked at that, and she looked at supplements, and she was told in no uncertain terms she wasn’t to do any of it, that she was to put sugar back in her diet, and how ridiculous it was to take it out. And when my friend argued back a couple of times about evidence, and bearing in mind she’s a smart lady and, but at the end of the day her prognosis, with treatment, is 12 months. And she said, from my point of view I want to do everything I can, and the retort was, “if you do any of these things then you will have a very miserable 12 months”, and that’s unacceptable.”

Participant CP378.

"Because I do get quite hot under the collar about, a lot of oncologists have a stock response, certainly around here... so either diet has no bearing whatsoever or, so here's what makes me mad. If a, if a client said, if a patient said to their oncologist, is it OK to still eat McDonald's, the oncologist would say, yeah, fine. If the, if the same patient says to that, is it OK to do a ketogenic diet, you know mainly sort of animal protein, fruit and vegetables and de, de, de, de, the oncologists would go, oh no I don't think so. And that just makes me mad, so that sheer closed mindedness to other forms of help and the fact that the oncologist actually, whether they realise it or not, has the almost, is almost in a God like position with the patient and that's sort of the, what the oncologist says the patient will do, so if the oncologist says eat McDonald's, the patient's going to do it..."

Participant CP387.

"I think oncologists need to, I suppose, be a bit more open to what we're offering really. I think we're open but I think they're (oncologists)... 'you're doing it my way or and food has nothing to do with it'."

Participant CP383.

However, it was also noted that this experience is not unique to patients affected by cancer, but also in other clinical areas:

"... but they sounded out the oncologist and the oncologist said, well if you want to waste your money that's up to you, and that's a theme that has occurred... In Parkinson's isn't easy. In (a Parkinson's disease charity) are extremely derogatory and quite, can be quite aggressive if they hear nutritionists are working with Parkinson's, so it's not easy there either."

Participant CP370.

This undertone of discord was felt by some participants to have an adverse impact on clients exposed to such conflict:

“I think they (clients) feel like it's one or the other, the two can't work together. And I'm very much of a, we're not opposed to each other, we can work together and I think that could be a bit of a problem and I think certainly specialists in the field, oncologists particularly can be very dismissive of the kind of work that I do.”

Participant CP375.

“...because I think it's very wrong, if a patient's made to feel that they're going against their consultant's wishes, or something like that, by seeing nutritionists.

Participant CP378.

Lack of communication between professions appeared to exacerbate the perceptions of discord, opposition or perceived hostility to NT, and emerged as a further barrier. Although CP positioned themselves as wishing to be collaborative and complementary to oncology, there were many examples of lack of communication or dialogue. Some participants described their attempts at engagement, but a strong thread emerging was of no response from the recipients of their letters, or of the client acting as bridge, or even resisting communication between NT practitioner and oncologist, all of which compounded the client's sense of conflict:

“I say to people, would you like me to write to your oncologist,..give this to your oncologist, the probiotic before you even consider taking anything. Ask your oncologist's advice... anybody who is happy to, I'm more than happy to write to them. A lot of people just say oh, I don't want them to know I'm doing this and I'm always saying it's far better if

everybody is singing from the same hymn sheet. It's good if we all communicate but, yeah, so I'm more than happy to write to doctors and I do on occasion write to them but sometimes the patients are, oh well, we don't want them to know or I'm not sure they approve of what I'm doing."

Participant CP383 (previously a nurse)

"Well, I've usually, unless the patient has not wanted me to, I've usually written a letter to their ...GP, their oncologist, whatever, telling them what I'm doing. Just setting it out and making very clear I'm not offering any kind of a cure, I'm offering nutritional support which will give the body an opportunity to, not even necessarily heal, but will have the ability to alleviate some of the side effects, and it has the ability to boost the immune system, and just generally help, and I list the nutritional supplements.

(Interviewer:...do you ever get replies?)

Hardly ever. It's interesting you should ask...or it's one or two lines...There's never been a response that shows any kind of interest ...but I'm so used to it, I ignore their lack of response and just plough on and do what I believe to be the right thing...I've got a tough skin. I think others don't."

Participant CP372.

Therefore a strong theme of discord, conflicting opinion, and lack of engagement between the NT and the client's oncologist was evident in the perspectives of challenges and barriers to practice for this cohort of CP. Some felt that a lack of professional recognition of NT contributed to the lack of engagement with oncologists, and that being considered as 'complementary and alternative medicine' led to the NT practitioner being viewed as oppositional to oncology:

“I think also the fact that nutritional therapy comes under the complementary, it maybe it’s just the terminology, complementary and alternative medicine is automatically the opposite side of the fence. I just, until that shifts it’s going to be a very, a difficult uphill struggle I think.”

Participant CP385.

In contrast with these perspectives, one participant felt that although her work with clients was not endorsed by oncologists, her approach was less subject to conflict and opposition, perhaps because the advice she gave pro-actively dealt with oncologists’ concerns about potential interactions between nutritional supplements and cancer treatments:

“I mean, a lot of the time I think because they don’t have the nutrition knowledge, they will just say, it’s fine but don’t expect much from it. Sometimes they will say, and what I tend to do is make sure that people are not taking things that will clash with their chemotherapy drugs, while they’re on the chemotherapy. So I usually put in a regime which is between sessions, and often I will get feedback back, well, yes, if you’re going to do it, that’s the way to do it, and we’re happy for you to do it like that. And actually I’ve never, ever had an oncologist saying no, don’t do that. They usually, so my feeling is they’re probably quite ambivalent about the input.

Participant CP380.

One participant did observe that these barriers arising from inter-professional dynamics have been coming down to some extent in the last ten years, but overall the theme was of lack of communication and positive engagement between CPs and particularly oncologists. The theme carried an undercurrent of frustration on the part of the NT, and which was felt to have an adverse impact on their provision of care for cancer patients.

In summary, by critically analysing qualitative data from interviews with cancer practitioners’ on their perspectives on working with cancer clients, three major themes emerged that are documented here for the first time. All

have potential to impact on the practitioner and the patient/client and identify areas of professional development need. Firstly, some practitioners may be distressed by, or have difficulty dealing with, the expectations of people with cancer. This may be compounded by working alone and/or having no connections with whom to share their feelings and by lack of appropriate training in managing emotional and psychological aspects of practice. Secondly, specialist training for NT cancer practice is considered to be poorly provisioned and in need of development, and thirdly, that connections with oncologists particularly are perceived to be difficult and in some cases potentially impacting on the client affected by cancer. Within their narratives, participants identified areas and ideas for improvements in practice which are documented in Chapter 7.

To complement the perspectives of the CP cohort, the views of NCPs on working with people affected by cancer will now be documented in Chapter 6.

Chapter 6. Findings of interviews with NT practitioners who do not work with people affected by cancer

In this chapter, findings are presented from interviews with eight NT practitioners who self-identified as non-cancer practitioners. This cohort provided perspectives on cancer practice, and particularly barriers that had prevented them working with people affected by cancer, or why they chose not to. The analytical framework developed for the narratives is presented in Table 11.

Furthermore, findings from the group interview with a practitioner committee, which acted as a consensus panel to discuss practice guidelines are then presented. Five of the six group interview participants self-identified as NCP. Table 13 sets out the analytical framework developed for the group interview

Table 11. Analytical Framework developed for NCP Narratives

Practitioner and practice characteristics	
Themes	Main categories emerging
Practice setting	Sole practitioner Multidisciplinary clinic Private medical facility Health & wellbeing / fitness centre, retreat Geographically remote
Practice workload	Full time NT practice Part time NT practice Combines individual client work with other NT work
Clinical interest	Mixed client case load Adults clients Paediatric clients Non-cancer specialist interest

Perspectives on working with people affected by cancer	
Themes	Main categories emerging
Interest or motivation	Witnessing cancer in close friend or family member Cancer patients needs not met for nutrition advice
Attempts to work with people affected by cancer	Requested work placement at NHS oncology centre Offered to volunteers at cancer charity Worked with client with pre-cancerous condition Works with cancer survivors on other health concerns Networking with CP Would be confident to advise on cancer prevention Started specialist cancer training
Views on cancer practice	Specialist areas of NT include cancer (and others) Should be restricted to specialist NT practitioners Complex and challenging Lack of clarity on cancer prevention Would refer to specialist NT practitioners
Barriers preventing cancer practice	Lacks specialist skills and knowledge Lacks confidence to work with people during treatment Not enough time for care needed Not approached by any clients affected by cancer Relationships between NT and medical profession
Means to overcome barriers	Specialist training Supervision, mentoring and support network Engagement with other professions Information resources Recognition of NT role in cancer care Guidelines and practice framework
Skills and training themes	
Themes	Main categories emerging
Specialist training needs	Emotional, psychological and communication skills In-depth knowledge of cancer and treatments Dietary approaches Safe practice

	Use of supplements
	Skills in empowering patient and family
	Specialist teaching clinic

6.1 Participant characteristics of the cohort of non-cancer practitioners

In this section, the NCP cohort is introduced, their characteristics are shown in Table 8. Participants were engaged in other areas of clinical work, including digestive system disorders, sports nutrition, addiction, autoimmune conditions, pregnancy, and food skills for people on low incomes. They undertook individual client work, workshops and teaching, and two also undertook other healthcare practice: pharmacy and teaching Pilates.

6.2 Perspectives of NCP on cancer practice

Although self-defining as NCPs, three participants described limited work with cancer clients but had found it difficult to break through barriers to develop this practice. Five of the cohort discussed experiencing cancer in a family member and some had given dietary advice. Exploring their experiences identified a number of barriers to practice and professional development needs that may support new entrants to this area of practice.

In summary, three major themes emerged, as summarised in Table 12.

Table 12. Summary of themes and sub-themes emerging from NCP interview data

Major themes	Sub-themes
1. Cancer patients have unmet needs for nutrition advice.	People close to NCP participants were affected by cancer Their needs for nutrition information were not met

2. cancer as a complex clinical problem requiring specialist skills	Cancer is complex There is risk in providing advice for people affected by cancer Specialist training is required
3. working with cancer patients requires specialist support and resources	Formal support structure is needed Networking to share research Access to full publications

NCPs recognised that people affected by cancer patients have unmet needs for nutrition advice during and after treatment, but they feel cancer is a complex condition that requires specialist training, and that specialist resources are needed to support safe practice.

6.2.1 MAJOR THEME 1 – cancer patients have unmet needs for nutrition advice.

In summary, NCPs perceived a need for nutrition advice for cancer patients. This observation of inadequate provision of nutrition advice came through clearly in the narratives of NCP participants, they recognise a need for providing this service.

It is certainly something I was very interested in and did consider, a really interesting area that, in fact people have approached me while I was still in training. A good friend of mine, her husband had advanced cancer in the lung and he was very poorly, and she did not get advice, adequate dietary advice at all. She would say to me, hurry up and finish your training so you can help us. Certainly my experience of other members of the family who have had cancer issues, prostate things like that, they've not been given any dietary advice either.

Participant NCP399

6.2.2 MAJOR THEME 2. – cancer is a complex clinical problem requiring specialist skills.

Within this major theme, participants described the complexity and seriousness of cancer and the risk for the client if a mistake was made, if inadequate advice was given:

I see it as something that's quite a serious health issue, and I don't feel that I have undergone any particular training in that area and so, yeah, when people have got something that's serious and potentially life threatening, I feel ethically that it's better for them to go to somebody that has done training in that area, and that's more likely to be able to help them, because it just feels completely wrong to be seeing someone and purporting to be able to help them when maybe that you can't, and that there's someone that can better help them. So really that's my modus operandum for passing them on like that.

Participant NCP388

This NCP, who is also involved in teaching NT, felt that there should be restrictions on cancer practice so that practice experience and/or specialist training were required:

... I don't know whether there almost needs to be some sort of more restriction around that, because I do feel that perhaps people shouldn't be working with cancer patients until they've done, although we, although it's part of what we touch on in the training, I don't think that it's enough really to be able to support somebody who's in a very critical condition. So yeah, I sort of perhaps feel that, there needs, that perhaps that should be an area that's ring fenced, people that have maybe done more advanced training or have been practising for a certain amount of time.

Participant NCP388.

“Post treatment I have no issue, quite comfortable with that, but it’s that, whilst they’re having their treatment and understanding the type of chemotherapy or radiotherapy they’re having, and if there are any interactions, because the last thing you want to do is to cause, or inappropriately, with all the best intentions, give the wrong advice. “

Participant NCP390 (also a pharmacist).

“...particularly when it comes to cancer ... the patients who come to nutritional therapists or other practitioners and they are dealing with something, depending on where they are in their treatment, still it’s life threatening and they feel safer to be taken care of by someone who is well trained ...”

Participant NCP392.

This major theme of cancer complexity requiring specialist training, is linked to areas of professional development, detailed in Chapter 7.

6.2.3 MAJOR THEME 3. – working with cancer patients requires specialist support and resources

This third major theme in NCP perspectives evidences barriers relating to specialist support and resources. Barriers included difficulties in accessing full papers once practitioners had finished formal training.

“Well I think it sort of depends what you have got access to, so I think for people that are studying, so if you’re maybe doing a Masters or something like that, then you’ve probably got access to online journals and that then gives you access to up to date research in the area, so that’s quite helpful. But I think perhaps lots of nutritional therapists don’t

have that access, so there's some sort of access I think through BANT, there's obviously CPD courses and things, but I think that a lot of the time we don't really have the latest up to date information and I think that, that's also potentially a bit of a barrier"

Participant NCP388.

"... it would be quite good if there was a central place that perhaps you could go with a group on a website so that people would collect perhaps their own research on, latest research on cancer, nutritional therapy and perhaps say to link on this website and then you could discuss the papers amongst yourselves as well."

Participant NCP398.

Specific resources were explored which NCPs felt would be needed to support their practice, such as information resources and access to evidence, and a structure to support practitioners. From these NCP themes, professional development needs emerged, reported in detail in Chapter 7.

Themes emerging from the interviews participants who self-define as non-cancer practitioners therefore provide, for the first time, perspectives on why some NT practitioners may avoid cancer practice, or have been unable to establish practice in this clinical area. Their major perspectives were that people affected by cancer have unmet needs for nutrition advice, but that cancer is a serious and complex condition deserving specialist training, and finally that specialist resources and support are needed for practitioners working with this client group.

6.3 Group interview with practitioner committee

A major theme of needing specialist information resources for cancer practice emerged from both CP and NCP perspectives. Within this, practice guidelines or frameworks emerged as potentially useful, this also emerged from the Phase 1 survey data. Therefore, a group interview explored this,

with a committee of practitioners in a professional association. This volunteer group of practitioners is responsible for providing a professional practice handbook for the association's members. The group included one participant who self-identified as a CP. In this section, themes emerging from this group interview on a specific aspect of professional development are reported.

The analytical framework for the group interview is reported in Table 13.

Table 13. Analytical Framework developed for Group interview

Themes	Main categories emerging
Role of guidelines for NT profession	Define safe practice Different to practice protocols Emphasize scope of practice and boundaries Especially important for newly qualified practitioners Recommend engaging with other professions Protects practitioners Protects the profession
Scope and contents	Can be general Can be specific For higher risk or complex clinical areas Compare with eating disorder practice guideline Recommend engaging with other professions

Themes emerging from the discussion were, principally, that guidelines act as a platform for safe practice and are linked to the regulator's professional practice guidelines (Complementary and Natural Healthcare Council, 2013). It was also felt that new practitioners may particularly feel they need a practice guideline, and that specific guidelines were important for particularly complex clinical situations or client groups, to define the scope of practice in that clinical field. They compared the needs for a cancer practice guideline with that for working with people affected by eating disorders. Within both guidelines the participants emphasized the need for collaboration and communication with medical professionals.

In summary, as part of the exploration of future professional development needs for working with people affected by cancer, a consensus panel explored aspects of professional practice guidelines, which they described as providing a framework or platform for safe practice that would also link to the regulatory framework. Particularly with certain clinical groups, there was emphasis in guidelines that NT practitioners must engage and collaborate with medical professionals.

Following the interview, the group asked this researcher to provide input into the further development of the cancer practice guideline and a letter template for practitioners to use with clients (see Research Outputs Chapter 11, section 11.2).

Chapter 7. Professional development needs

In this chapter, the professional development needs emerging from the CP interview data reported in Chapter 5 and the NCP interview findings reported in Chapter 6 are drawn together. This documents for the first time, three areas of professional development needs, which reflect the major themes of challenges and barriers in the CP narratives, and are congruent with themes emerging in NCP interviews of needs for those wishing to start cancer practice.

Firstly, improvements are urgently required to support practitioners to deal with emotional and psychological aspects of practice with people affected by cancer. Three potential solutions emerged from the narratives of both CP and NCP participants: appropriate training in managing these impacts, informal peer networking and formal supervision or mentorship. Secondly other developments in formal training provision were identified, and finally some proposals for improvements in the engagement with oncology professionals. Means to deliver this last area of professional development were the least tangible but some participants had seen some success with their own approaches that may provide some potential directions for future work. Developments in practical and information resources to support cancer practice were also identified, particularly access to research literature.

7.1 Supervision, mentorship and networking

In this section, elements are identified from CP and NCP themes on support for practitioners for emotional and psychological aspects of practice, and for supporting and sharing best clinical practice. As previously identified in the survey data in Chapter 4, Table 1, and in Chapter 5, Table 8, most NT practitioners, including CPs, work independently, and they identified a lack of formal and informal networks of support. As illustrated by participant CP372, (section 5.5.1, page 143), informal networks can provide much needed support.

A clear message of needing supportive connections therefore emerged, identified by CP and NCP participants, as informal or formal networks, or a process of supervision or mentorship.

Sometimes I think about setting up a network of cancer practitioners around the country who have got a resource base, shared information, maybe even a paid researcher, and a bit of a formula, I mean not a formula, formula obviously, but a, but a general protocol, but also a group of people who could meet with each other and discuss their difficult cases and. Sometimes I also think the only way we're ever going to get through this is joining up, being an individual is tough.

Participant CP387.

"I think it's important to have structures in place that practitioners who are working with a cancer patient, they find themselves supported along the way, both in terms of developing their skills but ongoingly they are supported, because it can be actually quite challenging, from my own experience, it can be quite challenging at times, and having that support, having that, knowing that somebody holds your back, it makes such a difference."

Participant NCP392.

when I worked at XXX I had a team of nutritional therapists and we had something like that going every month where I just got a speaker in and, or we discussed cases and it's just so beneficial in terms of learning but also sharing ideas, offloading difficult situations so a bit like supervision but more of a learning thing and just getting together and feeling that we're not so isolated so I think that could be something that would be not that difficult to set up... I've spoken to xxx at xxx and they agree it's a good idea but I think just everyone's busy and no one's actually made it happen yet but I really feel that that could be something quite easy that would really be very beneficial.

Participant CP382

Sharing best practice and mutual support therefore emerged as an important development for cancer practice, either connecting in person or remotely.

Therefore as well as informal peer support and networking, a process of formal supervision emerged as a supportive measure that practitioners would find valuable:

"...I'm in a supervision group so it was something I was very keen to set up because as a psychotherapist you have to have supervision. It's part of the protocol of being a therapist. But there is lots of nutritional therapy and yet we're still dealing with people who often have hugely emotional needs that aren't being met and so. And also just having difficult cases, it's really nourishing to get together with your peers and talk about issues.

Participant CP375.

During the time this research was being conducted, the professional association BANT introduced a pilot scheme for supervision, as part of their strategic plan to develop the profession, and some participants had been involved. The scheme was generally welcomed although it was felt that the depth of discussion should meet the needs of specialist practitioners, that supervisors should be appropriately experienced, and that telephone supervision would be welcome.

I did take part in the pilot programme last year, but I really didn't get anything out of it. The people that did, it was a very small group and the other, there were only, of the four meetings that I went to, I went to all four of them, but the other three people that attended, nobody else went to all four and I didn't feel there was enough experience amongst those other people to actually discuss anything as complex as cancer.

Participant CP379.

I think most of it would have to be via the telephone. I don't think the, people would either have to be prepared to travel or it would have to be

done via the telephone... I think, I think probably in my view and I've been doing this for I don't know how many, 13 years, but actually I want somebody who's been, who's more experienced than me which is why I go to xx and various other people that I know, xx and xx who've been doing it, who've had an extra ten years practice on top of mine. So yeah, that's I think, I would, I feel I would need somebody who, one, I respect and two, has more experience and somebody I feel comfortable with. I think they're, yeah, they're probably the three things that you would need.

Participant CP383

The perception of the supervision process was felt to be important for one participant:

I actually don't think supervision is the right word...I'd much prefer the word mentorship or, mentorship and preceptorship, which is what we used in nursing because supervision makes them feel they're still at school.

Participant CP395.

In summary, there was strong support for a framework or process that supports practitioner development in the form of clinical supervision or mentoring that is appropriate for cancer practitioners, and for informal and formal networking, to share best practice and provide peer support.

7.2 Specialist training

This section draws together the themes from CPs and NCPs on the needs for specialist training to work with people affected by cancer. For the first time, training development needs are documented for this NT practitioners who wish to work with people affected by cancer. This may inform a framework of specialist training for the NT profession.

Firstly, for many participants it was felt to be important to have some form of

professional certification, formal recognition or validation of specialist training, although one participant felt that non-specialists could give basic advice and all NT practitioners should be skilled in discussing cancer prevention.

“just even to say that this particular nutritional therapist with OK, a BSC, and a MSC and everything else but also has this certificate of proficiency and specific expertise in helping people with cancer and supporting them nutritionally. I think that’s really, that might be very helpful.”

Participant CP372.

So it would be, it would have to have gone through that process where it’s been validated as a certain level of information. I think who’d be putting it on as well...

Participant CP377.

In exploring the elements of training that participants felt were important, as previously identified in section 5.5, training in managing the emotional and psychological aspects of practice, including understanding patient expectation, emerged as important for practitioners working with people affected by cancer. Participants identified other skills and knowledge they considered important, including knowledge of cancer biology and pathology and detailed understanding of individual cancer types.

“I think, first and foremost I think they need a kind of a comprehensive overview of most aspects of cancer. I think first and foremost they need to know how to deal with the patient, to start with, because when you come out of school, out of nutrition school, you can only really do the basics...”

Participant CP395

“...well maybe it is something we have to specialise in because it is a specialist area, we have to have a good understanding of cancer itself, we have to have a good understanding of the medical procedures that people may be going, choosing to go through and if they don't choose to go through, what kind of protocol we can offer and if they do choose to go through the standard orthodox chemo and radio, how we best manage that...”

Participant CP375.

“I think instead of just having a generic cancer module I would definitely split it into the big ones, well all of them really, and make it much more detailed... Prostate cancer and breast cancer have got so many similarities so I do think that's important. Cancer of the oesophagus...Cancer of the stomach, bowel cancer...”

Participant CP384.

Skills to understand risks and clinical complexity emerged as important, as well as training in finding and critically appraising evidence:

“....What is this study actually saying? I think more, I mean that would be really useful in undergraduate courses as well, is to look, here's several papers, go away and let me, what do you actually think of them? What is actually being said here? Because quite a lot of the time, we just get abstracts and so we read the abstract, but sometimes the abstract isn't actually representative of what's actually in the rest of the study, so it would be quite useful to actually to have to read some full studies to see what's actually being discussed.”

Participant CP379

It was felt important to understand the patient perspective and the cancer journey. Specific skills in communicating with oncologists were also identified as important to some participants:

“But I feel that if we are going to provide a thorough and meaningful service to our clients we have to communicate with the GPs and the oncologists because until they understand what we’re doing, we’re never going to achieve this sharing of information and I’m a great believer in an integrative approach. So if you don’t know how to write to an oncologist or a GP you’re never going to achieve that end...”

Participant CP384.

For some participants, formal training alone was not considered enough, and experience in practice was felt to be important in acquiring clinical consultation skills. Communication skills were felt to be particularly important and for some a sense of working with people that involved intuition:

“...you know even doctors before the 1940s were not using evidence as part of their practice, they just got to know their patients very well, and had an intuitive feel for what was needed. So I’m all for evidence, but not on its own, I think you need, you need, you needed, I, may (be) ooh controversial, if you even need a calling, you know?...That there’s a feel for it that you need, you need a feel for people...”

Participant CP387.

In summary, training needs identified for the first time for NT practitioners working with people affected by cancer, include managing emotional and psychological aspects of practice, understanding the patient journey, specialist knowledge of cancer, how to access and use evidence. Skills in engaging with and communicating with other professionals also emerged

from participants' perspectives, which links with the next area of professional development need.

7.3 Improved engagement with mainstream healthcare professions involved in cancer care

In this section, the potential developments needs for the NT profession in better engagement with other healthcare professions are identified. This area of need emerged predominantly from CP narratives, and professional respect emerged as widely desired. For some, formal professional recognition was perceived as an improvement that could enable oncologists and other mainstream healthcare professions to recognize appropriately skilled practitioners. This links to the need for validated or accredited training that emerged, and a certificate of proficiency and a register of NT practitioners with specialist training were also proposed as desired developments. Some participants felt they would be better recognised if they could openly identify as CPs on their practice information and marketing material. Direct communication with oncologists as a group or individually, was proposed as potentially helpful, with perhaps a professional body taking the lead.

Some participants described strategies they had considered or attempted to improve communication. Making contact with oncology nurses was considered one potential route, since patients rarely see the same oncologist at each hospital visit. Skills in effective letter writing and presenting evidence were considered an important part of specialist training.

To summarise, developments in this area are linked to recognised professional training and appropriate skills in inter-professional engagement and communication. Better engagement at a group or professional body level also emerged as potentially useful.

7.4 Improvements in information resources

In this final section of professional development needs, improvements in information resources for NT cancer practitioners are reported. A clear theme emerging from CP and NCP narratives was a need to access evidence to support practice. A database of evidence for nutritional interventions was suggested, or a repository or forum where research could be shared.

“I mean it would be a lot of work for somebody or some people to organise but maybe I could help as well, but perhaps just have a database of papers, if there’s new papers and things coming out that people have read. To be able, to have some forum or something where we can post all of those. So not necessarily have group discussions, but just have a forum, a database of nutrients in prostate cancer, nutrients in breast cancer and or etc etc.”

Participant CP379.

“I think access to research papers, or just even part of a community where you’d maybe pay, I don’t know, £30 a year or whatever, a community, to say, every time there’s something new you send me a link, and then it’s up to me whether I look at it or not. Then I think you’re up to date, if that makes sense?”

Participant NCP390.

But also, to be honest, probably an ongoing resource, so again whether that’s a website or something like that because when you’re,...like you’re on your own. And to have somewhere to go where there’s reliable evidenced information ... Because obviously we have linked in or those types of groups where you can post things, but something more specialised where you can say, I’ve just found this study or this what I’ve found, and put it somewhere where you can, you know you’re going to go and get reliable information. But also as I say just having

more of a dialogue between, because it can only benefit everybody by having reliable information

Participant CP377.

Specific evidence on interactions between cancer treatments and nutrients was highlighted as important to include, and several felt that a process map or outline protocol, would be supportive especially for less experienced practitioners. This emerged from both cohorts:

“Yeah, a framework or a guide structure where you go through from one thing to the next and actually if this is an issue then what you would normally, there’s a red flag, you have to refer or do something else or whatever. Or if, assuming this, this, this and this then you carry along this line.”

Participant NCP397.

Therefore potential improvements in information resources such as evidence databases and practice guidance emerged from narratives of CP and NCP participants, to support practice with people affected by cancer.

To summarise, this is the first documentation of NT practitioner perspectives on working with people affected by cancer. Individual interview data with CPs and NCPs identified barriers and challenges to practice. Major themes included the emotional and psychological challenges experienced by CPs, the lack of formal recognised specialist training, lack of specialised support and resources, and lack of engagement between NT professionals and other healthcare professionals. Professional development needs have been identified from these narratives that provide evidence to inform training, support arrangements and information resources. These data have relevance for developing the practice of nutritional therapy of people affected by cancer.

Chapter 8. Discussion

8.1 Overview

This study is the first detailed exploration of the perspectives of nutritional therapy practitioners on working with people affected by cancer in the UK. A mixed methods approach, philosophically situated within the Pragmatic paradigm (Feilzer, 2010), collected and critically analysed data on the extent and context of NT practice with people affected by cancer. A survey was followed by in-depth exploration of practitioners' perspectives using interviews. CP interviews explored the lived experience of working with people affected by cancer and professional development needs. NCP interviews explored what they felt would be needed to embark on this area of clinical practice. Differences identified between CPs and NCPs in training and experience may help to identify specific knowledge and skills important for practice with people affected by cancer. Overall these data will inform future development needs of the NT profession in the UK.

Themes emerging from interviews that explored CP perspectives aligned closely with themes emerging from the NCP perspectives. Major themes emerging from the research were firstly that more support is needed for NT practitioners working with people affected by cancer, particularly as many may be working alone as independent practitioners. Participants identified needs for support to manage the emotional and psychological impact of working with people affected by cancer. A strong desire emerged for a professional framework to support evidence-based practice, and for peer engagement to provide mutual support. Secondly, it is clear that practitioners themselves feel that provision for specialist training needs developing, to prepare practitioners to provide evidence-based specialist care for people at various stages of the cancer journey, and the skills to manage the aforementioned emotional and psychological aspects of practice. Thirdly, improved communication and engagement with mainstream oncology professions emerged as strongly desirable. NT practitioners participating in this research are motivated to work in a complementary approach, but feel

their work many be opposed, or even remain undisclosed to some clients' oncologists. Training in inter-professional communication could be a useful part of the aforementioned specialist training, but other approaches to improve dialogue deserve to be explored in future research, which could examine the issues from the perspectives of other professions.

This discussion will first address the profile of the NT profession emerging from the data on practitioner characteristics. The extent of NT practice with people affected by cancer will be addressed and then practitioner motivation will be considered. The major themes and the professional development needs emerging from participant narratives will then be critically analysed.

8.2 Nutritional therapy practitioners portrayed in this study cohort

From the survey data, NT appears to be a (fairly) young profession with mature members who are predominantly female. NT has been practiced in the UK since the 1980's, with the first formal training offered in 1984 (ION, 2016) followed by the first undergraduate Bachelor of Science degree in 1998 at the University of Westminster (CTNM Editor, 1998). As a profession it is less established compared with almost a century of dietetics (Hutchinson, 1961).

During the last decade the NT profession has developed from a regulatory perspective (Granger and Watkins, 2014, Benbow et al., 2017) and comparing the phase 1 survey data with an audit of the 2006-2009 register shows a marked increase in practitioners with formally accredited training, which became available from 2009 onwards. This enabled practitioners to apply for registration upon qualifying, whereas prior to accreditation, practitioners needed three years of experience before becoming eligible to apply for registration via a professional portfolio.

The survey data on gender showing a preponderance of women NT practitioners concurs with data on gender in mainstream healthcare in the UK, where 77% all NHS employees and 90% nurses are women (NHS, 2016). The gender data on NT practitioners also agrees with data for dietitians, of whom 95% (8275/8733) on the UK register in September 2017

are female (Health and Care Professions Council, 2017), the same figure reported for Canadian dietitians (Gheller and Lordly, 2015).

Comparing with professions working outside mainstream healthcare, there are data on CAM practitioners in other countries. For example surveys of naturopaths and herbalist in Australia (Braun et al., 2013b) and New Zealand (Cottingham et al., 2015) reported over 90% identified as female. There may be a number of reasons for the gender imbalance in NT; independent practice may appear flexible and perhaps fit with women's other commitments. A recent study of occupational profiles of UK NT practitioners reported that 51% of the 408 practitioners surveyed were women with school-age children living at home (Benbow et al., 2017), which may be compatible with flexible working as an independent NT practitioner. There may be other social and perhaps cultural reasons for the gender imbalance in NT and in CAM overall; a systematic review of literature on social aspects of gender and providers and users of CAM (Keshet and Simchai, 2014) considered why women, particularly middle-class white women, are more drawn to providing and using CAM. The authors explored several perspectives including a theme of "privileged healthcare for privileged women" in the social constructs of CAM. However their analysis considered 'CAM' as a broad collection of practices and considers an overlap of some CAM practices with 'holistic spirituality', which may have less relevance for NT which is bioscience-based. The NOS for NT does include considering the needs of the whole person (Skills for Health, 2010c) but is based on the same principles of health and disease as mainstream healthcare. Keshet's (2014) analysis suggested that women may also be drawn to working as CAM practitioners as it positions them outside mainstream institutions that may be male dominated, it aligns with the nurturing aspects of feminine identity and gives a degree of independence and empowerment. However, none of these potential motivational factors or rewards emerged from the narratives of the NT practitioners taking part in this study, but motivation to become a NT practitioner *per se* was not explored in this study; the topic of motivation and reward was in relation to working with people affected by cancer.

Age and years in practice data suggests an 'average' NT practitioner in the study is in their late forties and has likely been in practice for five years or less, suggesting that NT may be a second career for some participants. This aligns very closely with Benbow's (2017) recent survey of the UK NT profession in which 41% of the 408 respondents had been in practice for up to 5 years, compared with 43% in this study. Furthermore, over half of survey respondents in this doctoral study had an additional Bachelor's degree or higher, most commonly in other health and life science subjects. This evidence of a high level of graduate entry to the NT profession may explain why many have opted for a diploma course to qualify, rather than embark on another degree, although there are now a number of post-graduate courses in NT that may suit science graduates (Nutritional Therapy Education Commission, 2017). The NT survey data agrees with an older study of 426 CAM practitioners in private practice in the UK (Andrews, 2003), more than half had turned to CAM as a second career and 14.8% had been nurses. These data may also inform the debate on the standard of training in the NT profession, which has been subject to some unfavourable comparisons with dietitians and nutritionists (Cade et al., 2010, Murphy and Girot, 2013, British Dietetic Association, 2014).

8.3 Nutritional therapy practice with people affected by cancer

Considering the extent of NT practice with people affected by cancer, the survey which recruited 31% (274/888) UK registrants, confirms that there is some interest in working with clients whose health concerns include cancer, 31% survey respondents self-identified as CPs, and a further 43% of survey respondents expressing interest in working in this area of clinical practice. CPs are therefore still a minority of the NT profession; particularly if the survey sample was biased towards cancer practitioners. If as a result of recruitment bias, all CPs in the NT profession were attracted to the survey, it suggests that less than one in ten registered UK NT practitioners are CPs. Typically within the CP survey cohort, working with clients affected by cancer was part of a mixed practice workload, although a handful of CPs (7/84)

defined themselves as cancer specialists who work exclusively with this client group.

Having identified that there are CPs in the UK NT profession, it is reasonable to question here why the services of an NT practitioner would be relevant for people affected by cancer. Firstly, people affected by cancer are reported to be interested in diet and lifestyle and their needs for accurate information may not be met during or after cancer treatment and in survivorship (Beeken et al., 2016, Williams et al., 2015). NT practitioners may be meeting this need for some. Secondly, widespread interest in the use of nutritional supplements amongst people affected by cancer is well documented (McLay et al., 2012, Schofield et al., 2010). NT practitioners, with training in the use of nutritional supplements, but situated outside of mainstream cancer care, may be seen as one professional group that offers advice for these needs. The issue that will be returned to in section 7.7.2, is related to the concerns about cancer patients using such supplements during active cancer treatment.

8.4 Motivation and rewards in NT practice with people affected by cancer

In exploring motivation to work with people affected by cancer in this study, a personal cancer journey or witnessing cancer in a loved-one often emerged. Another motivator for CPs was meeting cancer survivors who were enthusiastic about good nutrition as part of their survivorship. Rewards emerging from CP narratives were being able to support people through their cancer treatment and giving those clients a sense that they could do something positive for themselves by eating well. For some CPs who were also cancer survivors, the concept of 'giving back' was a powerful reward, and personal stories emerged of feeling that mainstream provision of nutrition advice was not enough for people affected by cancer. This aligns closely with the first major theme emerging from NCP narratives, that cancer patients have unmet need nutrition advice, which is supported by the literature (Beeken et al., 2016, Williams et al., 2015, Polley et al., 2007). By comparison, in an exploration of motivation amongst therapists providing touch therapies in specialist cancer care and hospice settings (Mackereth et

al., 2009), a personal experience of cancer was also cited, by 9/51 participants. Some of Mackereth (2009) study participants had moved across to therapeutic touch therapies (which include massage, reflexology and aromatherapy) having worked in beauty care. Others described themselves as mainstream healthcare practitioners who were providing CAM because they felt it may help where mainstream cancer care had been insufficient. Participants in that study were working in hospices and in NHS cancer centres, whereas the NT practitioners in this doctoral study were working outside established cancer care settings. Therefore despite the differences in settings and in the types of CAM therapies practiced, there were some common themes of motivation between Mackereth's (2009) study and the NT practitioners in this doctoral study. Within both studies there were practitioners who had had a personal cancer journey, and some who had perceived a need for additional help for people affected by cancer, and felt motivated to provide it.

8.5 A theme of isolation -*"I do work on my own...It's very solitary, it really is."*

A picture of widespread NT practice as sole practitioners with clients affected by cancer (and other health concerns) emerged from this doctoral study. This has implications for the practitioner and for clients. 80% of all survey respondents were working as sole practitioners at least some of the time, and over half exclusively. There were few working in groups or multidisciplinary practices and none working within mainstream cancer care settings. Other implications of separation from mainstream healthcare will be discussed in section 8.7. The theme of isolation echoed through CP narratives, where a common yearning was expressed for connection with other practitioners with whom to share ideas and burdens. Two aspects of isolation emerged in relation to working with clients affected by cancer; being alone with the psychological and emotional impact, which will be discussed in 8.5.1, and being alone in making decisions about client care (see section 8.5.2). Needs for support for both of these were clearly articulated.

8.5.1 *“what would be nice for me is to have somebody I can call and say this is what’s happened to me today.”*

The negative psychological and emotional impact emerged as a major theme in barriers and challenges to practice in CP interview narratives. It was not clearly apparent from the Phase 1 survey data from the CP cohort, demonstrating the inadequacy of a survey to explore issues in depth. It was however a minor theme from the NCP survey data, on reasons why NCPs chose not work with people affected by cancer. Within the CP interviews it was widely articulated as a challenge that they endured. One CP intentionally restricted clinical hours each week to reduce the psychological impact, and another had decided to see fewer people affected by cancer, due the grief experienced after deaths of clients. Most CP participants managed a mixed caseload of clients with cancer and clients with other health concerns, and some participants noted the variety was welcome. Perhaps for some this was also a means of reducing the impact of working with people affected by cancer. This may merit exploration in a further study. Three (of thirteen) CP participants articulated that they were not particularly affected by these aspects of cancer practice, of whom two had the longest experience in practice. One of these described her own strong professional network from her training cohort, with whom she could share *“everything”*. She had thereby established for herself what other CP participants had expressed a need for – peer support. The third CP participant who expressed that she was not challenged by the emotional aspects of practice had just started seeing clients affected by cancer, having completed her own cancer treatment. This was not explored further in the interview with this participant, intentionally, since it may have taken the discussion into areas beyond the practitioner perspective.

Stress and distress experienced by CP participants arose firstly due to unrealistic expectations of NT, especially clients with advanced disease hoping that NT would hold back their disease. Loss and grief were experienced when clients died, especially after a long professional relationship. These same sources of stress have emerged from research

with mainstream professional groups working in cancer care. For example, much has been written about their impact in oncology nursing, which has a high rate of burnout (Finley and Sheppard, 2017, Kutluturkan et al., 2016, Duarte and Pinto-Gouveia, 2017), in doctors working in oncology (Blanchard, 2017, Zajac et al., 2017, Hlubocky et al., 2017, Turner et al., 2017) and radiotherapists (Singh et al., 2017). Nurses and other professionals working with people affected by cancer throughout the journey to the end of life may experience serial bereavement, (Wenzel et al., 2011), and the need to manage the effects of this in the cancer workforce is recognised. In a study of burnout in 221 nurses working in cancer care in Portugal (Duarte and Pinto-Gouveia, 2017), some psychological factors were predictive of burnout, for example experiencing personal distress and being self-judgemental were associated with greater susceptibility to experiencing burnout. Resilience has been identified as an important factor for the wellbeing of healthcare professionals, and has been explored from several perspectives in cancer care. For example in interviews with 10 nurses in palliative care, (Ablett and Jones, 2007) a personal commitment to working in palliative care and a sense of purpose emerged as contributing to resilience in such an emotionally challenging role. In the CP cohort in this doctoral study, the sense of commitment and empowering their clients came through strongly as rewards, this may explain why CPs endure the stressful aspects of their practice and continue to work with people affected by cancer. A number of personal factors are said to contribute to resilience including self-awareness and social competence, but importantly family cohesion and social resources (Friborg et al., 2005). Resilience is also said to need 'hardiness' and coherence (Ablett and Jones, 2007). Common to many studies of resilience and burnout in healthcare professionals in cancer care is the observation that support for practitioners is important to maintain the resilience and well-being of the practitioner (Friborg et al., 2005). Within this doctoral study, CP participants described a lack of skill to deal with psychological and emotional impacts and having no-one with whom to share these burdens, potentially increasing their risk of burnout. Therefore working independently presents potential challenges for CPs, and as a work arrangement it therefore deserves to be considered from the perspective of practitioner wellbeing.

8.5.2 Professional networking to share best practice

Working in isolation must also be considered from the perspective of patient/client safety, with regard to how much support and peer review of practice is taking place for potentially isolated practitioners. NT practitioners participating in this study articulated that there were few routes of support available to working with people with cancer. Indeed, when survey respondents and interview participants had the opportunity to suggest what support they would like, they identified networking, mentoring and supervision. Comparing these findings with the literature on supporting practitioners who are isolated or dispersed, an integrative review and thematic synthesis (Moran et al., 2014) examined means to support healthcare practitioners. The authors, working in Australian healthcare where the workforce may be dispersed over a very large geographical area, were considering how geographical remoteness may contribute to professional isolation and may impact on clinical governance as well as practitioner wellbeing. They analysed 43 studies from several countries including Australia, Canada, USA, Guatemala, Kenya, South Africa and Scotland, covering medical, nursing and allied health professionals including dietitians and pharmacists. They concluded that four types of support could be effective; supervision, training, professional network and mentoring, and that communication technology can support these across dispersed professional groups. These same types of support were identified by NT survey respondents and both CP and NCP interview participants, as desirable to support their practice with people affected by cancer. CPs and NCPs were specific in needing these to overcome their professional isolation and share best practice, as well as support with psychological and emotional aspects of their practice, as discussed in 8.5.1. This highlights an important area to pursue for professional development, and it might then be expected that NT practitioners would welcome introduction of this framework of support.

Clinical supervision, a formal engagement between professionals to enhance learning and competence (Pollock et al., 2017) is used in other health professions including mental health professionals (Barnett and Molzon,

2014), nursing (Edwards et al., 2006) and allied health professions (Moran et al., 2014), although there are different models and objectives. It may provide a framework to address some of the needs identified in this doctoral study. A systematic review of clinical supervision in healthcare professions (Pollock et al., 2017), which included ten reviews and 19 primary studies was initiated by changes in statutory supervision of midwives in the UK. The authors analysed data for different models of delivery, which were conducted mostly as groups, and concluded that there was insufficient evidence for any specific framework for supervision for implementing in the midwifery profession. Further research within the NT profession would be helpful to identify a suitable model, and particularly the arrangements for including participants that may be physically distant. Pollock's (2017) review included supervision that was all conducted face-to-face, but in considering the potential relevance for NT practitioners, many are working independently and separately. However, it has been acknowledged (Moran et al., 2014) that reaching practitioners that are dispersed and isolated may require other means to be developed for supervision, and some NT practitioners in this doctoral study suggested that telephone or video- conferencing would be a suitable approach. A mixed methods study of 189 allied health professionals in rural Australia (Kumar, Osborne et al. 2015), using an on-line survey followed by semi-structured interviews and focus groups, explored the use of clinical supervision that took place by telephone and video-conferencing, as well as face-to-face. The authors reported that supervision to support isolated practitioners and enhance clinical governance was broadly supported and valued by practitioners. Time and physical distance were factors to consider, and unlike the UK NT profession studied here, the Australian study was of employed practitioners. NT practitioners are more likely to be self-employed and therefore would likely need to spend unpaid time on activities such as supervision, which highlights the importance of providing a service that meets their needs and is easily accessible.

The NT professional association BANT launched a pilot scheme in 2016 for voluntary clinical supervision (British Association for Applied Nutrition and Nutritional Therapy, 2017) and a small number of CP and NCP interview

participants in this study had attended local BANT supervision groups. These groups were organised on a regional basis and open to all BANT members regardless of experience or clinical interest. However, CP participants in this study felt that the level of discussion in their local groups was more directed to business development and not suited to their interest in working with people affected by cancer. They felt that a specialist group led by an experienced CP would be of interest. There are few examples in the literature of specialist clinical supervision with independent healthcare practitioners, but one small study with 15 CAM therapist working in cancer care explored practitioner perspectives on supervision (Mackereth et al., 2010). Focus groups were used with practitioners, including unpaid volunteer therapists, who were providing complementary therapies at five cancer centres in north-west England. Themes emerging identified that participants viewed clinical supervision as part of self-care and professional development. This would concur with a role for supervision to provide a supportive role for NT practitioners working with people affected by cancer, by enhancing their professional development and supporting their wellbeing and resilience.

In addition to supervision, an interest in mentoring emerged from some narratives of both CP and NCP interviews and the survey, for supporting less experienced practitioners in working with people affected by cancer. Mentoring is used in healthcare as part of professional development and support, is usually dyadic in structure, with one-to-one interactions between a professional and a more senior colleague (Rabbetts, 2017, Chatburn, 2004). As an example, a professional development network established for dietitians in one health care organisation in Canada (Vogt et al., 2015) provided professional networking and formal mentoring. In a survey one year after the programme was launched, users were able to enhance their knowledge, reflect on their strengths and connect with other dietitians through the programme. This could inform the development of a model for the UK NT profession.

Whilst supervision and mentoring represent formal arrangements for individual professional development, other frameworks for peer support and

engagement may also be relevant for NT practitioners working with people affected by cancer. Professional networking for mainstream healthcare professions in cancer care is well organised on a national and European scale, producing newsletters, practice guidance and opportunities for networking, for oncologists (Morgan et al., 2016) and nurses (Campbell et al., 2017). The specialist oncology dietitians group at the BDA has over 300 members and four sub-groups interested in palliative care, upper gastrointestinal cancers, head and neck cancers and haematology (British Dietetic Association, 2017). None of these frameworks of support were evident for the NT practitioners in this study, which underscores the risks of isolation of NT practitioners working with people affected by cancer, from the interview data and the survey data. The data does show there is interest in developing and using these frameworks of peer connection to enhance practice and the practitioner experience. Some CP participants expressed interest in collectively developing guidance notes, evidence resources and documents to rationalise client care, which could emerge from professional networking arrangements. NCP participants expressed needs for these types of guidance to support new entrants to cancer practice.

Therefore this research identified that NT practitioners who work with people affected by cancer have unmet needs for professional frameworks of support, that will help CPs to manage the psychological and emotional aspects of cancer practice, and facilitate peer-review of practice and support evidence based care.

8.6 Training for NT practitioners working with people affected by cancer

In this section, the findings on training for working with people affected by cancer will be discussed. This will consider existing training standards, comparison with other healthcare professions, and the perspectives emerging from this study on future training needs.

8.6.1 Cancer practitioner qualifications

Data on NT training from the survey revealed that CP respondents were significantly more likely than NCPs to have additional health and life science (HLS) qualifications ($p=0.009$). This may be coincidental, it may be that NT practitioners with additional HLS training are drawn to working with people affected by cancer because they appreciate the challenge of the complexity of the condition. It may also convey that there are potential advantages conferred by additional HLS training that have enabled working as a CP, and the implications deserves further consideration. Firstly, additional HLS knowledge, and skills in accessing and appraising evidence and clinical information, could be particularly useful for this complex clinical field. These skills are taught in accredited NT courses, and would be expected to have greater emphasis on the accredited post-graduate NT courses, but having broader experience of critical analysis of research data from other HLS training would be an advantage. There may be an additional advantage of familiarity with the language of cancer care. It has also been suggested that CAM practitioners with substantial knowledge of biomedicine may have an advantage in attempting to integrate CAM with mainstream care by reducing negative social categorization of CAM as 'unscientific' (Nugus et al., 2010). Research on teamwork in healthcare suggests that collaboration is more likely where the different professions involved have a shared mental model of healthcare (Weller et al., 2014). This may mean that mainstream healthcare professionals may feel less concerned about advice being given to their cancer patients when they see it is being provided by a CP with recognised HLS credentials. Also, there were a range of HLS qualifications amongst CPs, and it could be that being qualified in nursing would have certain advantages (such as understanding the patient perspective, cancer treatments and the NHS 'system') whereas a biochemistry graduate may have a different advantage, for example strong skills in critical analysis of evidence on drug-nutrient interactions.

However, in this study, participants with additional HLS training still perceived difficulties relating to collaboration and communication, therefore

this implies that a high level of bioscience-based training, or an HLS ‘identity’ do not necessarily facilitate better engagement between NT practitioners and mainstream professionals. This will be returned to in section 8.7, in considering the major theme of inter-professional dynamics and lack of engagement as a challenge to practice.

8.6.2 Specialist training for NT practitioners working with people affected by cancer

The need for specialist cancer training emerged as a major theme in CP and NCP narratives and in the survey data. Lack of recognised specialist training provision was considered a challenge or barrier to practice for CPs, and for NCPs interested in this area. Whilst mainstream healthcare professions including medicine, nursing and pharmacy have organised routes of formal specialist training and supervised practice (British Medical Association, 2017, Gail, 2008, Ikesue and Oishi, 2008, RCN, 2016), this research underlines the inadequacy of provision for specialist NT training. CPs in this study had organised their own specialist learning through a number of routes. Both survey and interview participants, NCPs and CPs, felt that formalised training was needed for working with people affected by cancer. Across the study cohorts, participants felt it should include clinical knowledge, including treatments that cancer patients may receive, the potential for interactions between treatments and nutrients, and psychological and emotional aspect of working with this client group, including managing client expectation. CP training needs to include skills in accessing, critically appraising and communicating evidence, from the perspective of best practice and patient safety. Study participants reported accessing peer-reviewed evidence, but acknowledged difficulties in accessing some full publications and expressed a need for better access to, and regular updates on, the literature. CPs with additional health and life sciences training may be more able to work with the complexity of evidence, and this concurs with the data that CPs are more likely than NCPs to have this additional sciences training. Study participants expressed support for access to a database of evidence on nutrition and cancer, including some suggestions of providing this for a subscription or

funding a researcher. It could be said that there are already extensive databases of health research. However, there are gaps in the evidence of relevance for people affected by cancer, as discussed in Chapter 1 and recognised in the literature (Inoue-Choi et al., 2013, Norat et al., 2014, Pekmezi and Demark-Wahnefried, 2010, Davies et al., 2011). Practitioners therefore need to be able to access and critically appraise current evidence, and new evidence as it arises, and also communicate with clients appropriately about gaps in the evidence base. There may also be a role here for practice guidelines, which also emerged from the study as desirable, particularly for newly qualified practitioners. Referring to the desire for professional networking discussed in section 8.5.2, experienced CPs could collaborate to produce evidence-based documents that would support best practice. The professional association BANT is establishing a database of evidence on nutrition that its members may access (BANT, 2017) and an editorial board member for cancer nutrition would be a useful development.

Considering aspects of safety, another important element to include in training for CPs is the importance of reporting adverse events that may occur in relation to nutritional supplements. There is a recognised system in the UK for monitoring adverse events associated with medication – the ‘yellow card’ system, which can also be used to report suspected adverse reactions to herbal medicines and other complementary products (MHRA, 2017). Overall for complementary medicine, reporting systems for adverse events are less developed than the formalised pharmacovigilance which the ‘yellow card’ system contributes to (Robinson et al., 2011). Some CAM professions including osteopathy and chiropractic, along with physiotherapy, have their own reporting system for adverse events relating to their treatments (Robinson et al., 2011).

The final skill set that emerged as important, to include in specialist training are skills in communicating with mainstream healthcare professional. This links also to the third major theme in this study, of difficulties in engagement and communication between NT and mainstream professions.

8.7 Relationships between NT and other healthcare professions working with people affected by cancer

This section will discuss the third major theme of the research study, which is situated in the inter-professional dynamics between NT and other health professions involved in cancer care. Lack of engagement with mainstream healthcare professionals, and lack of understanding or opposition to NT practice, emerged from the survey data and emerged strongly in CP narratives as barriers and challenges to practice. These were identified as an area needing improvements at a profession-wide level, as well as for professional development at the level of individual practitioners. Three sub-themes of inter-professional discord perceived by study participants will be discussed here: engagement and communications with mainstream healthcare, specific concerns about safety of NT interventions during cancer treatment, and apparent differences in perspectives on nutrition between mainstream cancer care professionals and NT professionals.

8.7.1 Communication and engagement between mainstream healthcare and NT.

NT is identified as a bioscience-based complementary medicine modality, rather than alternative to mainstream healthcare, and accredited NT training courses are intended to prepare practitioners for collaborative practice (Complementary & Natural Healthcare Council, 2017). All CP participants in the study practiced outside the NHS, where most cancer patients will be treated, which inevitably separates the NT profession from the mainstream cancer care community, likely reducing or precluding regular professional engagement. The survey data showed little evidence of referral to CPs from mainstream healthcare, therefore there appear to be no formal routes of communication or dialogue between NT and mainstream healthcare. Some study participants felt that being labelled 'CAM' was disadvantageous for professional recognition, that it positioned NT as oppositional to mainstream healthcare. Although many different healthcare professions work in the NHS and private hospitals delivering cancer care, the NT practitioners in this study

perceived that the opposition to their practice was principally from the medical profession at the level of the individual client. Some study participants perceived opposition from dietitians, and as discussed in section 1.2.1, there is hostility to NT as a profession from the other two nutrition professions, that is, dietitians and nutritionists. This section will however focus on the practitioner level.

The perceived opposition to CPs appeared not to be communicated directly, but was conveyed by their clients, for example by clients resisting offers from their CP to write to their oncologist because they felt that seeing an NT practitioner would be opposed. It has already been discussed (section 1.6) that many cancer patients use special diets and nutritional supplements, as well as other CAM interventions, often without informing their mainstream healthcare providers, which is a concern that was shared with participants in this study.

Much has been written on relationships and communication between CAM and mainstream healthcare including clinical guidelines for safe integration of the two paradigms in fields such as cancer care, as developed by the Society for Integrative Oncology (Greenlee et al., 2014, Deng et al., 2013, Deng et al., 2009). As it is a very broadly researched field, the focus in this discussion will be matters of relevance to the themes emerging from this study with NT practitioners. Where practitioners are seeking to collaborate across professional boundaries or a paradigmatic divide, positive engagement may be more likely when there is a shared philosophy of care and mutual respect (Nugus et al., 2010, Gray and Orrock, 2014). Since NT is a bioscience-based practice, a common paradigm of health and disease could be expected, unlike for example the paradigmatic difference between mainstream medicine and homeopathy (Sehon and Stanley, 2010). If the NT practitioner and the oncologist have a shared understanding of cancer, its treatment and the journey of the person affected by cancer, and a common view of the role of evidence in practice, this might present the basis of better professional engagement between the two. Communication between professionals about patients/clients conveys information that is important for care, and several studies have looked particularly at improving communication between CAM

and mainstream professionals. For example, studies with both professional groups have examined practitioners' preferences for communication (Ben-Arye et al., 2007, Schiff et al., 2011). Questionnaires sent by mail or e-mail surveyed 333 physicians and 241 CAM practitioners on inter-professional collaboration, which was found to be supported by 69% doctors and 77% CAM practitioners (Ben-Arye et al., 2007). Following this, a Delphi process was used to develop recommendations for the format for communicating, which were then tested in a further survey of opinions, amongst 473 doctors and 781 CAM practitioners (Schiff et al., 2011). Four elements considered important to inter-professional communication and collaboration emerged and letters were preferred. Schiff (2011) concluded that they should convey the patient's diagnosis, with explanation of terminology if needed, the aim and plan for treatment, comment on the quality of CAM supplements where used, and the potential for interactions between conventional and CAM interventions. It is worth noting these studies took place in Israel where CAM is widely used and often partly funded through health funding organisations, but they provide useful data that may inform inter-professional engagement and communication for the NT profession. Therefore referring back the second major theme of this doctoral study with NT practitioners, the need for specialist training, this should include training in the elements of communication with doctors about their patients, informed by the four element format proposed by Schiff (2011).

8.7.2 Specific concerns about interference with cancer treatment

This section will discuss an important area of patient safety and potential discord between NT and mainstream healthcare, the use of nutritional supplements, which is reported to be widespread in people affected by cancer (Truant et al., 2013). This is of concern to oncologists and other healthcare professions, due to a number of risks, particularly interference in treatment (Roberts et al., 2005). Firstly, as previously discussed in Chapter 1, section 1.6, the potential for interference in radiotherapy by the concomitant use of antioxidant supplements is concerning, antioxidants may also have an effect on some types of chemotherapy, and there is an

additional potential for interference by some supplements in drug metabolism. It has been suggested that a further potential for interference in treatment is not within the body of the client, but more in the client's decision-making about treatment, which has been studied in the Breast Cancer Quality of Care (BQUAL) study of women diagnosed with early breast cancer (Greenlee et al., 2016). BQUAL prospectively studied 1158 women with a diagnosis of non-metastatic breast cancer, followed for four years at three centres in the USA. The study found that use of nutritional supplements was significantly higher amongst women who delayed or declined having chemotherapy that was clinically indicated. These women were more likely to use a number of CAM interventions including herbal medicine, but not more likely to use CAM modalities considered to work on the mind-body axis, such as a meditation. They were also more likely to have negative perceptions about chemotherapy and be more concerned about side effects. It was not clear whether they decided to use nutritional supplements because they have already decided against chemotherapy, or had decided against chemotherapy because they felt nutritional supplements would be a better choice. In contrast, women for whom chemotherapy was considered to be discretionary, due to a marginal clinical benefit, were not more likely to use nutritional supplements. The authors did note that the actual number of women declining chemotherapy was small, 34, which was 11% of those for whom chemotherapy was clinically indicated. It does however provide support for the concern that the use of nutritional supplements and other CAM may be associated with delay or refusal of recommended treatment for cancer. This is a specific concern that needs to be identified and understood within the NT profession, which seeks to work in a collaborative and integrative manner with mainstream healthcare. Much has been written about people affected by cancer opting out of treatment, and a review of the literature on declining mainstream treatment (Verhoef et al., 2008) examined this in relation to patient characteristics. Declining active treatment was associated with individual characteristics of being self-directed, wishing to retain control and also more active in their own health. Furthermore, a literature review of factors influencing the use of CAM by cancer patients (Weeks et al., 2014) developed the concepts of interactions between multiple

factors in the decision making process, that differ by stage in the cancer journey. The concept model encompasses factors that influence these decisions by people affected by cancer, which include beliefs, social and cultural factors, as well as demographics and the nature and stage of their particular disease. Therefore the concern that NT practitioners may influence people affected by cancer to decline or delay treatment may or may not be valid, but needs to be considered in the light of these other factors contributing to the client's decision making. It would also be a useful element in specialist training for CPs for practitioners to understand how people affected by cancer make decisions about their treatment.

Overall therefore the literature suggests that the intersection of using nutritional supplements and delaying or declining treatment is a complex one, with the characteristics of the client a factor. Having accurate facts about nutritional interventions in cancer would be important for people making these decisions, therefore the ability of an NT practitioner to access and critically appraise evidence on diet and nutritional supplements, and clearly communicate it to a client, will be important. Equally important would be the need to be clear to the client where there is no evidence on supplements, and to proceed with patient safety foremost in mind. As described in section 8.6, the discussion of the first major theme of CP perspectives in this study, unrealistic expectations of NT clients affected by cancer was one aspect of the psychological impact on CP participants. People affected by cancer considering delaying or declining active treatment may have unrealistic expectations of nutritional interventions, particularly supplements, and this highlights the importance of appropriate practitioner skills to accurately advice the client. NT practitioners surveyed and interviewed in this study identified that they want to work in a complementary and collaborative way for patients affected by cancer, and therefore awareness of this area of concern for oncologists, and their important role in providing appropriate evidence-based advice, is important for NT practitioners to appreciate. This may help to resolve a potential source of conflict between the NT and oncology professions. Further research could

also explore the perspectives of oncologists on engagement with NT working with people affected by cancer.

8.7.3 Different perspectives on nutrition between the NT profession and mainstream cancer professionals?

This section will discuss the third sub-theme within the theme of lack of engagement and understanding with mainstream professionals; discord was perceived to arise from different perceptions of nutrition and its role in cancer. Some CPs reported that clients were sometimes told by their oncologists that diet doesn't matter. CP participants that are also cancer survivors also reported experiencing this personally. Within these lines of communication there will be a component of interpretation. However, on the surface it appears to represent a paradigmatic divide between NT practitioners, whose professional aim is to optimise the nutrition of their individual clients, and some oncologists who appear to perceive no role for nutrition. It has already been reviewed in Chapter 1, section 1.5, that there is evidence that the needs for nutrition information for people affected by cancer are not always met. There has also been recent research with healthcare professionals in the UK on factors influencing the provision of information to cancer patients, on smoking, diet, exercise and alcohol (Williams et al., 2015). An on-line questionnaire was used with 460 health professionals involved in working directly with cancer patients, including 126 nurses, 34 doctors and 11 allied professionals including dietitians. Two thirds of respondents reported awareness of some lifestyle guideline, most commonly on diet (50%) with nurses being more aware than doctors. 57% respondents reported giving advice on diet to *'the majority'* of their patients. Advice was more likely when the healthcare professional was a nurse, and was more likely when the professional was aware of the existence of guidelines for diet and lifestyle. However, advice was less likely to be given by a professional if they did not believe the advice would affect cancer outcomes. Barriers to advising patients about diet included: lack of patient interest, lack of belief by the practitioner that diet would make any difference to outcomes, thinking that the patient would not change their behaviour, not

wishing to blame the patient and cultural barriers to discussing weight. In Williams' (2015) study therefore there were differences in perception amongst doctors working in cancer care of the benefit of diet and other lifestyle changes for people affected by cancer, and that may affect the messages their patients received. This does add some support to the perception of conflict or opposition experienced by CP participants in this doctoral research, that some clients may be given a negative view of the importance of diet by their oncologists. However, accurate appropriate communication from the CP to the client, and communication with the client's oncologist would be helpful. This highlights again the need for CPs to be skilled at critically appraising and communicating evidence to clients and to other healthcare professionals.

In summary therefore there are a number of factors contributing to lack of engagement or opposition from mainstream health professions to NT practice with people affected by cancer. Potential improvements emerging from this research include training for CP in appropriate communication with mainstream healthcare about their clients. CP awareness of oncologists' concerns about interactions between nutritional supplements is also important. Communicating evidence-based advice for cancer clients will play a pivotal role in improving engagement between NT and mainstream cancer care. Beyond the practitioner level of engagement, there is also a place for initiatives at a profession-level to improve engagement.

8.8 Comparison between survey and interview findings

Overall, considering the professional development needs identified from this research, the major themes in the perspectives of NCPs were all aligned with the major themes in the CP narratives. There was wide agreement between the survey and interview phases on the needs for specialist training and the barriers arising from the lack of engagement and perceived opposition from mainstream healthcare. One significant difference between the survey and the CP interview findings was that the survey did not clearly identify the challenge experienced practice of the emotional and psychological impact of

working with people affected by cancer. This may reflect the questionnaire design, and also underline that individual semi-structured interviews are more suited to explore perspectives in depth.

8.9 Conclusions

In conclusion, this study has explored for the first time, the extent and context of NT practice with people affected by cancer in the UK.

Perspectives of a sample of NT practitioners have been explored in depth on working in this area of clinical practice. The study identified that CPs were statistically significantly more likely to have additional training in health and life sciences than NCPs and have been in practice for longer. These differences have provided insight into specific knowledge and skills important for practice as a CP, and important to acquire for those NCPs wishing to embark on working in this area of clinical practice. Major themes emerging from the interview phase suggest firstly that CPs experience a psychological and emotional impact of working with people affected by cancer, compounded by predominantly working alone and being professionally unconnected. This may be improved by developments in professional frameworks such as specialist clinical supervision, mentoring, and networking which may also underpin evidence-based practice. The second major theme emerging was the need for recognised specialist training which should include technical and clinical skills and knowledge, skills in managing client expectation and the psychological and emotional impact of practice, and skills in accessing, critically appraising and communicating evidence. A further skill set to include would be effective communication with other healthcare professionals. The third theme emerging was associated with barriers in communication and engagement with mainstream cancer professionals. Appropriate written communication from CPs about their clients might also help to improve engagement. Opposition to NT practice with people affected by cancer may arise due to concerns about safety of using nutritional supplements, particularly during active cancer treatment, and differences in opinions on the value of nutrition for people affected by cancer. The importance of CPs giving accurate evidence-based advice to

clients to enable them to have a realistic expectation of nutritional therapy was highlighted. Engagement at the level of the profession may also contribute to better understanding between the professions. These data on the practice of NT for people affected by cancer will be used to inform and support the development of the NT profession and contribute to safe effective practice.

8.10 Contribution to Original Knowledge

This research contributes original knowledge in a number of ways. Nutritional therapy (NT) practice in the UK with people affected by cancer has not been previously explored in any detail in the published literature, therefore this research has the potential to make a significant contribution to research and practice in this professional field.

Findings from this research have demonstrated that NT practitioners are actively working with people affected by cancer, and many more wish to do so. The study identified that practitioners working with people affected by cancer are more experienced and more likely to have additional training in health and life sciences, and identified that practitioners want formal specialised cancer training. Furthermore, this study has identified for the first time that there are high levels of lone working. This may compound the effects of working with clients with serious health concerns, and have a psychological and emotional impact on some practitioners that they need additional skills and support to manage. It emerged that practitioners want more support for practice such as a formalised system of specialist supervision, mentoring and networking.

The individual patient now has access to unparalleled levels of health and nutrition information of unknown quality on the internet, and cancer patients are reported to have unmet needs for reliable advice on nutrition (Polley et al., 2007, Beeken et al., 2016). How NT practitioners access and use evidence to inform clinical practice had not previously been critically evaluated until now, this study suggests that practitioners may refer to

evidence but also want further training and support in accessing, critically appraising and communicating evidence.

Furthermore, the research data confirms that, within the cohort studied, that nutritional therapists are rarely employed within the NHS or incorporated in NHS specific care pathways for patients with cancer, and report receiving cancer clients mostly by self-referral. These patterns of work impact on the dynamics of the relationship between mainstream healthcare professionals and nutritional therapy practitioners, and may affect patients/clients who consult them. The research findings suggest that the practitioners participating in this study want to work collaboratively and complementary to mainstream cancer care, but there is perceived opposition and lack of engagement. Some underlying concerns contributing to this apparent discord between mainstream healthcare and nutritional therapy have been explored and potential improvements considered. Issues emerged about compatibility of nutritional supplements with cancer treatment, lack of skills in communicating with oncologists, and difference of opinion on the potential role of nutrition for people affected by cancer.

Finally, the voice of the practitioner has for the first time been heard, in exploring their perspectives on their practice, their motivation and reward. Many participants in the survey and interviews commended this research project and its importance in supporting nutritional therapists to work with people affected by cancer, typified by:

“I hope that this research will be useful in bringing together all the health care professionals who work towards supporting people with cancer to become well again.” Participant #217, NCP.

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8.11 Further research

A number of areas emerged from this research that deserve further exploration. Firstly, it would be important to collect practitioner feedback after implementing the professional development measures emerging from this

research, for example for the specialist CP training and supervision. Secondly, to explore the perspectives of mainstream health professionals including oncologists on the role of NTs in working with people affected by cancer. This could be done perhaps after some developments in NT training and supervision have been implemented. A third area of research could usefully focus on the practice of those providing nutritional advice who are not registered, but as previously noted this is a large potentially diverse population of practitioners who by their lack of registration are difficult to identify.

Chapter 9. Limitations

There are a number of limitations of this research which will be discussed in this section.

9.1 Study population

The study participants were intentionally restricted to registered NT practitioners, because recruiting only registered practitioners had the advantage of reflecting the regulated profession, with a known set of training and practice standards. It also addresses the lack of precision in survey populations that has been identified as a limitation in other research with CAM practitioners (Molassiotis et al., 2005, Bensoussan et al., 2004a, Braun et al., 2013a, Novak and Chapman, 2001b).

The study has not explored the extent of practice by unregulated nutrition practitioners and this remains an area of potential concern, but conversely it documents a professional group that can be identified by potential clients seeking nutrition advice. Similarly, the perspectives were not sought of other CAM practitioners, such as herbalists and naturopaths, who may also give nutrition advice and may also be working with people affected by cancer. By design these are beyond the scope of this work but further research with these groups may be valuable.

9.2 Verification of registration

There was no definitive mechanism for ensuring that only registrants took part, since requiring a registration number for example, would have prevented anonymization. One survey question did ask for registration route and responses were checked against respondents' stated years in practice, since registration routes changed in 2010. One survey respondent's stated age, years of experience and claimed route of registration were incongruent.

The research was publicised through the largest NT professional association (BANT) which requires professional registration for its members. However, it

is possible that unregistered practitioners took part in the research, a recent survey of occupational profiles of NT practitioners in the UK (Benbow et al., 2017) reported that 81.6% were registered with the CNHC and 86% were members of BANT, therefore there are practitioners self-identifying as NT that are not registered. However, Benbow's (2017) survey also included non-practicing NT graduates, as part of an exploration of occupational profiles.

9.3 Generalisability of the data

The participant sample represented 31% of the NT register at the close of the survey, which meets the target for representativeness for the population surveyed, according to (Draugalis and Plaza, 2009). However, the survey did not use a random sample and was publicised with information that it was focusing on working with people affected by cancer. Therefore it may have disproportionately attracted practitioners with an interest in this area of practice, and hence data may not be representative of the overall profession. Conversely, the perspectives of those who did participate has relevance for those practitioners, their views deserves to be considered even if they do not represent the entire UK NT profession. Since there was a high degree of agreement on professional development needs for working with people affected by cancer, these deserve to be offered to the profession for those that may benefit from them.

There were 21 interviews conducted, but this collected qualitative data with no intent of generalisability of findings, instead to explore with a small sample of practitioners, purposively selected to represent a range of professional characteristics. The range of practitioners interviewed was narrow and the question of bias deserves to be considered, as discussed next in section 8.4.

9.4 Bias

The research was devised and promoted by the chair of the NT training accreditation board (NTEC) who could be perceived as an authority figure, thereby emphasizing a social desirability effect in the responses given by

participants. The use of a self-administered anonymous survey was seen as the best approach to mitigate against this (Roxas and Lindsay, 2012), although the role of anonymity to increase accuracy in surveys has been questioned (Bethlehem, 2010, James, 2006, Khazaal et al., 2014, Krumpal, 2013, Lelkes et al., 2012).

In the interview phase, the impact of the interviewer on social desirability effect may have been greater, although conversely the position of the researcher as a practitioner may have enabled deeper exploration of perspectives on the basis of a shared experience. Some social desirability effect may have been evident in the discussions of training, in that the role of the doctoral researcher within the profession to be involved in training accreditation, and also delivering some training. This is difficult to control for, but there was strong agreement between the anonymous survey data and individual interviews on the need for recognised specialist training.

9.5 Relationship between study phases

A further area of limitation may arise from the relationship between the two phases of the study, particularly the use of preliminary themes from the survey to inform the interview phase. One possible limitation would be that the interviews were constrained by the framework of the survey themes. However, the semi-structured interview approach enabled participants to discuss their perspectives within general themes, such as rewards experienced in practice. One significant difference between the two phases was that the major theme of emotional and psychological impact of working with people affected by cancer was not evident in the survey data. This suggests that the interview process was sufficiently open to enable other themes to emerge that were important to interview participants.

9.6 Group interview limitations

Finally, the group interview which explored the role of practice guidelines, was limited in scope and very brief, due to unforeseen time limitations in the

meeting at which it took place. Further research with practitioners would be needed to underpin development of guidelines for professional practice.

Chapter 10. Conducting professional research as practitioner and as a regulator

This chapter, which reflects on aspects of my research journey, is written in the first person for authenticity.

The shift in me as a researcher has been surprisingly large. From test tubes, culture plates, and medical devices, which are manageable, countable, 'verifiable', touchable, and existing superficially as one single reality, to exploring the multiple realities of the lived experiences of a practitioner.

Mezirow would ask me to reflect on not only my assumptions but the source of my assumptions, and to use those reflections for transformative learning, in which my frame of reference changes in a process of growth (Kitchenham, 2008). Is there evidence that I have learned anything other than how to 'do' research? When I read the reflections on the 'doing' part of the research, like coding and analysing data, it seems that the largest shift in my perspective is that I cannot assume that what I read or see is *the* reality, it is only one reality, and that there will be other realities uncovered by other researchers, that are valid. Opening them up requires that ability to critically unpack ideas, in an attempt to understand, not to simply to find '*the truth*' as there will be more than one truth. Two words illustrated this for me so beautifully in the early stages of the research – a survey respondent gave the shortest, and yet most enigmatic reply to a question about barriers to working with people affected by cancer ... "the NHS" was her reply. With no context, no opportunity to open up a dialogue and say "what do you mean?" it was left, as simple and as complicated a reply, that defied coding, defied interpretation, but to the respondent encapsulated her feelings on this.

Setting out...

Researcher reflection in qualitative work has particular value for researchers from within a profession (Le Gallais, 2008) who have a duality of role described as the 'insider-outsider' dilemma (Hellawell, 2006), who may

exploit their position within the research domain, by using their understanding of language, symbols and common purpose (Burns et al., 2012, Doykos et al., 2014).

During the research proposal process, I used critical reflection to map three domains of my work – clinical practice, professional regulation and research. This made me first consider my motivation, and uncovered some fears, about the research process in general, and my intended work in particular. Critical analysis of my assumptions exposed my preconceived ideas and beliefs that may frame or distort the process of research (such as designing questions to fit my ‘agenda’). I reflected on an apparent sense of moral imperative for pursuing this research; that it had an important dimension of improving accountability, as well as practice, for my profession. Although my early reflections on my motives were superficial and uncritical, on deeper reflection I also sensed the weight of ego involved, and this was emphasized when I reflected on what failure or ‘success’ in this research might mean personally. If I failed to complete the research I would feel a personal failure, and if my findings were awkward for the profession I would have to bear that responsibility.

An outsider on the inside, or vice versa

I had some concerns of the implications of possibly uncovering an unflattering portrait of the nutritional therapy profession, the potential impact on me within my professional network. These concerns reinforced for me the need for transparency and criticality, and above all a commitment to use the research output to influence practice. The data suggested my fears of unsound practice were unfounded, that peer-reviewed literature is used by practitioners but that more skill would help them use it more effectively, and that formalised specialist training, evidence-based guidelines and resources, and practitioner peer support are considered by cancer practitioners to be of value. This gave me a sense of relief but also a nagging doubt that my sampling was biased or that participant responses had a considerable amount of social desirability bias. Reflecting on my assumptions on the practitioner perspective before developing my data coding systems enabled

me to be more critical in my interpretation of participants' responses. However, considering my widely known role in professional regulation, then a degree of social desirability bias in this study was inevitable (Wouters et al., 2014, Krumpal, 2013), that even using an anonymous survey may not prevent (Lelkes et al., 2012). As a researcher I needed to be aware of this bias and looked for examples to refute my fears that study participants were telling me what they thought I wanted to hear. I reflected on where my knowledge of NT practice came from – firstly my own NT practice – but as a former life scientist I questioned if I was typical. Then the data confirmed that I may indeed be quite typical, as many other CPs had additional health and life science training. I reflected on my knowledge of current NT training through my accreditation role – and reflected that the training courses I had assessed were designed to underpin evidence-based practice, but acknowledged that not all training courses are fully accredited. I reflected on my experience assessing registration portfolios and the evidence practitioners needed to provide in their case studies. I reflected on my own experience as a CP and felt the raw nerve of grief from losing clients, and the sense of hopelessness for clients with very advanced cancers who came looking for a miracle that I couldn't deliver.

I used all of these sources of knowledge about NT practice and training as 'triangulation' for the data I was collecting, to give some degree of comfort that the data I had was authentic.

Stepping across and bridging the divide...

Embracing qualitative methods has been a major shift in perspective, a journey of transformational change in my attitude towards research paradigms and in my attitude towards social research in general. When I first began the doctoral programme I had doubts that qualitative research was of equal value to quantitative research, or even could be interesting. This goes back a long way to my attitudes as a young scientist that only numbers and measurements count, and that objective measurement is the only way to 'do research'. Mezirow described major shifts in perspective as Transformational Learning Theory (Mezirow, 2000), which can be emancipatory (Mezirow,

1990). This resonates with my experience of the process. According to Zull (2002), reflective learning in adulthood builds more complex layers of connections upon existing ones. When a new experience attempts to make neural connections (Zull 2002) that are discordant with an existing neural pattern, a feeling of discomfort is said to develop, which coincides with Mezirow's 'disorientating dilemma' that precedes transformational shift (Mezirow, 1990). Only after starting content analysis on the survey data did I begin to really appreciate that the qualitative exploration would be of value for understanding the practitioner perspectives. I also realised I had a degree of fear of the qualitative data, of not having enough of it, and more importantly, a fear of the process of qualitative data analysis, which was new to me. This I believe was my 'disorientating dilemma'. Overcoming this was revelatory but has been one of the most challenging parts of my research journey. As the data 'opened up to me' it became easier to reflect on my move away from positivism and the quantitative paradigm. Reflection reinforces experiential learning (Scanlan et al., 2002) and resonates with constructivist educational theory, that reflective learning as an adult constructs meaning in the mind of the learner, rather than simply receiving it from the mind of the teacher (Taylor and Lamoreaux, 2008). As a mature learner I have been able to reflect back on previous quantitative research work in life sciences that was, although apparently objective, framed by subjective judgements, and to identify where a qualitative dimension would have enhanced the work. I reflected on the vast difference between the surety for a quantitative researcher to calibrate their instruments and produce standard curves, (as I would once have done), in contrast with complex responses I was collecting in my qualitative research. It felt at first like working blindfolded, and when I embarked on the interview phase I was still pleased to have the quantitative data from the survey as a 'yardstick'. This transition phase reinforced my choice of following Mixed Method research principles, and I reflected on whether this is due to an inability to 'let go' of quantitative methods. However, I concluded that it reflects my personal pragmatism and being drawn to Pragmatism as a research paradigm (Hannes and Lockwood, 2011, Feilzer, 2010, Morgan, 2007, Johnson and Onwuegbuzie, 2004) that acknowledges the multi-layered nature of social

phenomena, that can be explored using the most appropriate method for quantitative and qualitative facets.

Having read Onwuegbuzie's work on mixed methods (Leech and Onwuegbuzie, 2009, Onwuegbuzie et al., 2011, Johnson and Onwuegbuzie, 2004) and reflecting on typology and legitimation in my research programme, I have therefore constructed my own conceptual landscape of how qualitative and quantitative perspectives can be applied in a complementary manner. The approach of Layder (1998) in Adaptive Theory, based on critical realism fits well with my pragmatic approach to methods selection and with my affinity with Pragmatic mixed methods. Layder's (1998) approach offers a pragmatic solution to whether theory should be developed inductively or deductively, by allowing both to take place during the research programme; he appears to sit as a bridge between positivism and interpretivism (Layder, 1998). However, if I was to embark on another research journey, my choice would be to use fully qualitative methods design to explore further some of the themes emerging in my research.

Chapter 11. Research Outputs and Implementation

11.1 Research outputs

During the course of the research a number of posters have been presented and papers published.

The first article was presented as a poster and won the prize for best poster at the 2013 CAMSTRAND conference in 2013:

Granger, C.A., Polley, M.J., Pilkington, K. and Draper, A. 2013. Understanding the professional characteristics, needs and experience of nutritional therapy practitioners working with cancer patients. *European Journal of Integrative Medicine*. 5 (6), p. 579.

In 2014 a poster was also presented at the CAMSTRAND conference and then published:

Granger, C.A., Pilkington, K., Draper, A. and Polley, M.J. 2014. Working with people affected by cancer – Phase 1 of a mixed methods exploration of practitioner perspectives in nutritional therapy. *European Journal of Integrative Medicine*. 6 (5), pp. 613-614.

Granger CA, Watkins K, Protecting patients through professional regulation: Audit of registration of nutritional therapy practitioners via a grandparenting process. *European Journal of Integrative Medicine* - April 2014 (Vol. 6, Issue 2, Pages 220-225, DOI: 10.1016/j.eujim.2013.11.006).

In 2015, the survey data and early interview data was presented in an oral presentation CAMSTRAND conference and then published:

Granger, C.A., Pilkington, K., Draper, A. and Polley, M.J. 2015. Barriers to working with people affected by cancer: Preliminary qualitative data from a mixed methods exploration of practitioner perspectives in nutritional therapy. *European Journal of Integrative Medicine*. 7 (6), p. 681.

In 2016, a research bursary was awarded by the Society for Integrative Oncology to enable the research findings to be presented at their New Investigator Forum oral presentation. A poster presentation was also given:

Granger, C.A., Pilkington, K., Draper, A. and Polley, M.J. 2016. Working with people affected by cancer –mixed methods exploration of practitioner perspectives in nutritional therapy. Society for Integrative Oncology 13th International Conference. Miami, Florida, USA 05 to end of 07 Nov 2016. New investigator forum oral presentation, poster presentation.

A further paper has been prepared with detailed analysis of the phase 1 survey and has already been submitted for publication to one journal, but declined, therefore this will be revised and resubmitted to another journal:

In preparation:

Granger, C.A., Pilkington, K., Draper, A. and Polley, M.J. Working with people affected by cancer – a national survey of nutritional therapy practitioners.

11.2 Research implementation

One of the intended functions of a Professional Doctorate programme of research is to advance practice or learning within a profession (Kot and Hendel, 2012), or in a transdisciplinary manner (Costley and Lester, 2012), such that research of relevance to the workplace or practicum is conducted. Providing 'authentic leadership' within a profession has also been suggested as a potential role for professional doctorate holders (Fulton et al., 2012).

This doctoral researcher, as chair of the UK voluntary body for training accreditation, is well placed to influence the professional frameworks for working with people affected by cancer. She will act as a direct advocate for these professional development measures within the professional body BANT, which has the largest number of NT practitioner members, and will directly advocate within the accreditation body NTEC, that she currently chairs. A report on these proposals will be presented to BANT and NTEC councils at the completion of this doctoral project.

Professional developments emerging from the data are identified below with actual or intended actions. Implementation of some recommendations has already been initiated during the later stages of the study.

11.2.1 Supervision, mentorship and networking for practitioners who work with people affected by cancer

- Clinical supervision - A proposal will be discussed with BANT council that they offer specialist clinical supervision by video conference or phone conferencing, led by one or more experienced CP.
- Mentoring – this will be explored further with BANT council, as there is no current mentoring scheme.
- Networking – the doctoral researcher will establish a closed CP ‘Linked In’ page linked to the BANT closed page, for discussion between CPs on practice issues. Further developments with this on-line networking can include news alerts on training events and research news.

11.2.2 Specialist training for working with people affected by cancer

- Post-qualification – the action required is to establish post-qualification courses for CPs, with a provider of accredited NT training. Training should include cancer biology, diagnosis and treatments, the cancer journey, accessing and critically appraising evidence and communicating in practice, dietary considerations and the safe use of supplements, communications between NT practitioners and mainstream healthcare professionals. Case-based assessments could be used to test knowledge. Implementation of this action has already begun, firstly the doctoral researcher is working with the Institute for Optimum Nutrition to deliver 3-day and 1-day courses on nutritional advice for people during and after cancer treatment. Secondly, the doctoral researcher is also working with Penny Brohn Cancer Care to provide training for NT practitioners to deliver dietary advice to people having cancer treatment.

11.2.3 Improved engagement with mainstream healthcare professions involved in cancer care

Four areas are identified that the doctoral researcher is directly involved in, arising from this research. The overall aim is to better understand the potential routes inter-professional dialogue involving the NT profession.

- Training in appropriate communications – this forms part of specialist training (see section 11.2.2 above)
- Inter-professional networking – the doctoral research is exploring further opportunities for engagement through the British Society for Integrative Oncology, and is now involved in the organising committee
- Local inter-professional collaboration – the doctoral researcher is working with a regional cancer centre to develop dialogue between NT practitioners, dietitians, oncologists and nurses, to develop common understanding of shared aim for cancer nutrition, this action is in progress and is being facilitated by a charity, Penny Brohn Cancer Centre, with Bristol Oncology and Haematology Centre.
- National inter-professional collaboration – the doctoral researcher is also now a member of professional workstream of National Institute for Health Research collaboration on nutrition and cancer, contributing to producing information resource for people affected by cancer. This collaboration is working to develop dialogue between NT practitioners, dietitians, oncologists and nurses, to develop common understanding of shared aim for cancer nutrition.

11.2.4 Improvements in information resources

- Practice guidelines – the doctoral researcher will work with BANT professional practice committee to update guidelines on working with people affected by cancer.

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Appendix 1 – Ethics Approval



APP. NO. 12-13-17: Granger Resubmission

RESC 26 June 2013 Minute 1.3.5

PRIVATE AND CONFIDENTIAL

Carol Granger
The Cottage at the Severals
Woolbeding
West Sussex
GU29 9RJ

9 September 2013

Dear Carol

App. No. 12-13-17,
Name: Carol Granger - School of Life Sciences
Mode: MPhil/PhD,
Supervisor: Marie Polley

Title: Understanding the Professional Characteristic, Needs and Experiences of
Nutritional Therapy Professionals working with Cancer Clients

I am writing to inform you that your resubmitted application was considered by the Chair of the University Research Ethics Sub Committee and has been approved.

The Chair has made the following comment, which you should address:

"The only slight concern is that the reference to the professional body is a bit hidden in the small print - in fact I did not even see it the first time I read the PIS. Participants are not likely to notice it, and given the concern by RESC, I would be happier if it was at the end of the main section - not in the small print. Especially since it is a very oblique reference to the possibility of being reported - that in itself is buried within their Code of Practice".

If your protocol changes significantly in the meantime, please contact me immediately, in case your ethical approval needs to be amended/extended.

In the meantime I wish you every success with your research.

Academic Services Department
101 New Cavendish Street
Cavendish House, University of Westminster
London, W1W 6XH
T: +44 (0) 20 7911 5051
E: H.Kelly01@westminster.ac.uk
westminster.ac.uk/research



A charity and a company limited by guarantee
Registration number 577816 England
Registered office 309 Regent Street London W1B 3UW

Yours sincerely



Dr Bob Odle
Acting Secretary, University Research Ethics Committee

cc. Chair, University Research Ethics Committee
Supervisors
Research Degrees Manager

I am advised by the Committee to remind you of the following points:

1. Your responsibility to notify the University Research Ethics Committee immediately of any information received by you, or of which you become aware, which would cast doubt upon, or alter, any information contained in the original application, or a later amendment, submitted to the University Research Ethics Committee and/or which would raise questions about the safety and/or continued conduct of the research.
2. The need to comply with the Data Protection Act 1998
3. The need to comply, throughout the conduct of the study, with good research practice standards
4. The need to refer proposed amendments to the protocol to the University Research Ethics Committee for further review and to obtain University Research Ethics Committee approval thereto prior to implementation (except only in cases of emergency when the welfare of the subject is paramount).
5. You are authorised to present this University of Westminster Ethics Committee letter of approval to outside bodies, e.g. NHS Research Ethics Committees, in support of any application for further research clearance.
6. The requirement to furnish the University Research Ethics Committee with details of the conclusion and outcome of the project, and to inform the University Research Ethics Committee should the research be discontinued. The Committee would prefer a concise summary of the conclusion and outcome of the project, which would fit no more than one side of A4 paper, please.
7. The desirability of including full details of the consent form in an appendix to your research, and of addressing specifically ethical issues in your methodological discussion.

Appendix 2 – Study information for participants

Understanding the Professional Characteristic, Needs and Experiences of
Nutritional Therapy Professionals working with Cancer Clients Participant
Information and Ethics Approval

Researcher - Carol Granger MBANT

Research Supervisor - Dr Marie Polley, University of Westminster

You are being invited to take part in a research study on Nutritional Therapy for cancer clients. There is evidence that nutrition can impact on cancer incidence, recurrence and outcomes, that cancer patients and survivors seek information on diet and the use of supplements, but that other professionals involved in cancer care have concerns about the use of nutritional measures during cancer treatment. The aim of the research is to explore the perspective of nutritional therapists (NT) working in cancer care. This will explore barriers experienced by cancer NT's, their access to and use of information on cancer, their views on training provision and other professional development needs and support. We will also seek to understand better the relationships and communications between NT's and other professions working in cancer care and communications with them. Overall this research seeks to provide evidence that will support the development of NT in cancer care.

The study will involve:

1) Completing an anonymous on-line questionnaire that is open to all registered NTs in the UK. The questionnaire will collect demographic data, including training and years in practice, and ask for your level of interest in working in cancer. If you indicate you work in cancer, it will ask for your views about information resources, perceived barriers to practice and any resources that you feel would help support cancer practice for NTs. This will take around 20 minutes to complete.

2) We will invite some or all of those who indicate they work in cancer, to take part in focus groups.

The researcher is registered with the Complementary and Natural Healthcare Council (CHNC); all research is being carried out in accordance with the CNHC code of Conduct (<http://www.cnhc.org.uk/assets/pdf/1-006.pdf>)

3) You will receive feedback on the research programme, that may also be published, after the analysis has been completed.

Please note:

- Participation is entirely voluntary.
- You have the right to withdraw at any time without giving a reason.
- You have the right to ask for your data to be withdrawn as long as this is practical, and for personal information to be destroyed.
- You do not have to answer particular questions either on questionnaires or in interviews if you do not wish to.
- Your responses will be confidential. No individuals will be identifiable from any collated data, written report of the research, or any publications arising from it.
- All personal data will be kept in a locked cupboard on University premises.
- Please notify us if any adverse effects arise during or after the research.
- The researcher can be contacted after participation by email (carol.granger@my.westminster.ac.uk) or by telephone on 07582 783425

(Click Next)

Introduction

All responses are confidential and anonymous. By taking part in the questionnaire you are indicating your consent for your responses to be used in the research.

You will be able to move between pages by clicking Next or Back

Introduction

The aim of this research project is to understand the professional characteristics and needs of nutritional therapy practitioners in the UK. The research will also look particularly at the support needed for working with people affected by cancer, for those who already work in this area and those who may wish to in the future. It will explore practitioners' views and experience, and will identify practitioners' needs for professional development. This will help training providers, professional associations and other organisation that support the profession.

All responses are confidential and anonymous. By taking part in the questionnaire you are indicating your consent for your responses to be used in the research.

You will be able to move between pages by clicking Next or Back

The first section is for all registered nutritional therapy practitioners. It will ask about your practice setting, other healthcare practices or therapies that you may offer, and your situation regarding working with people with cancer. It will also collect information on training, registration and experience.

(The paper copy will state:

When you have completed the questionnaire please return in the stamped addressed envelope provided; all responses are anonymous.)

Q1. Please indicate the type of practice(s) or locations you work in

Choose all that apply

☐ Sole practitioner

- ☐ Multidisciplinary premises
- ☐ Group nutritional therapy practice
- ☐ NHS facility
- ☐ Private medicine facility
- ☐ CAM centre or service for people affected by cancer
- ☐ Other - please define (open text box)

Q2 Please indicate any other health practices or therapies that you also offer, choose all that apply.

- ☐ Acupuncture/Traditional Chinese Medicine
- ☐ Aromatherapy/Reflexology/Massage
- ☐ Chiropractic/Osteopathy
- ☐ Coaching/Counselling/Psychotherapy
- ☐ Dentistry/Medicine/Veterinary medicine
- ☐ Healing
- ☐ Herbal medicine
- ☐ Homeopathy
- ☐ Naturopathy
- ☐ Nursing/midwifery
- ☐ Physiotherapy
- ☐ Other complementary therapies
- ☐ Other conventional healthcare
- ☐ Other – please define (open text box)

Q3 When you first applied to register with the NTC or CNHC, you would have applied by a particular route determined by your training and experience. Please indicate which route you applied through; choose one.

If you were transferred to the CNHC from the NTC register, please indicate the route that you first followed to register with the NTC.

As a reminder, information on each route is provided

- ☐ **NTC Grandparenting Route A** - experienced practitioners with evidence of three years safe independent practice. Portfolio included training records and two full clinical case studies to demonstrate competence
- ☐ **NTC Route B** - practitioners with NT qualifications that were not NTC accredited or mapped, with less than three years experience. Applicants demonstrated that their own training met the core curriculum
- ☐ **NTC Route C** with additional evidence – practitioners whose qualifications were partially mapped by the NTC to the Core Curriculum. Applicants provided evidence of filling the curriculum gaps with CPD or reflective writing
- ☐ **NTC Route C** without additional evidence– for practitioners whose qualifications were fully NTC accredited or fully mapped by the NTC to the Core Curriculum
- ☐ **CNHC Full portfolio** – experienced practitioners with evidence of three years safe, independent practice, Portfolio includes training records and two full clinical case studies to demonstrate competence
- ☐ **CNHC Guided portfolio** – practitioners whose qualifications were partially mapped by the NTC to the Core Curriculum, Applicants provide evidence of filling the curriculum gaps with evidence of CPD or reflective writing
- ☐ **CNHC Fast-track** - for practitioners whose qualifications are fully NTC accredited

- ☐ **I can't recall**

Q4 Approximately how many years have you been in practice?

_____years

Q5 Please indicate your nutritional therapy qualification. If you have more than one please indicate your highest level of NT training; choose one.

Reminder - if you registered via the NTC Grandparenting Scheme, you would have been awarded the NTC Certificate of Competence, which is a level 5 diploma.

- ☐ NTC Certificate of Competence / Diploma / Foundation degree
- ☐ BSc/BSc(Hons)
- ☐ PGCert/PGDip
- ☐ MSc

Q6 If you have other further or higher education qualifications, please indicate the level(s). You can choose more than one.

- ☐ Diploma/Foundation Degree
- ☐ Degree
- ☐ Master's
- ☐ Doctorate

Q7 For your further or higher education qualification(s), please indicate the subject area(s). (This question will appear for each response to Q6. Non-responders to Q6 will not see Q7)

- ☐ Other NOS-level CAM qualification
- ☐ Health and life sciences
- ☐ Other - please define (open text box)

Q8 Please indicate your age

___ years

Q9 Please indicate your gender. If you are transgender, please indicate your chosen gender

- ☐ **Female**
- ☐ **Male**

Q10 Thinking about working with people affected by cancer, how would you define your level of interest and/or activity? Please choose one.

In this study, cancer clients are defined as nutritional therapy clients/patients whose primary health concern is, or includes, cancer, that is

- *Active diagnosis of cancer, previous treatment or diagnosis of cancer; seeking advice to optimise health as a cancer survivor, or prevention of progression from an identified pre-malignant condition*

I'm Not interested in, or I choose not to work with people affected by cancer

- ☐ *I'm Interested or willing in cancer work, but not active with cancer clients at present*
- ☐ *Active in cancer work, but this is not the only clinical area I work in*
- ☐ *I consider myself a specialist cancer NT practitioner*
- ☐ *Other – please define (open text box)*

For participants who indicate that they do not work with cancer clients, responding to Question 10 either:

- ☐ *I'm Not interested in, or I choose not to work with people affected by cancer*
- ☐ *I'm Interested or willing in cancer work, but not active with cancer clients at present*

An open text box is then offered with the statement:

Q11 This box is for any comment you may like to add about why you choose not or do not work with people affected by cancer

Q12 Please tell us about any resources, training or other support that you feel might help you to work with cancer clients, if you wished to in the future.

The Questionnaire then ends with

Thank you for participating in this research.

Section 2 This section is for practitioners working with cancer clients.

In this section we ask your opinion about information sources, training and possible future support, for your work with cancer clients. We also want to know your opinion about barriers or challenges you may experience, and knowledge and skills you feel are important for in cancer work. At the end of the section there will be the option to volunteer to take part in a focus group to discuss these issues in more depth.

Q1 What particular skills and knowledge do you feel are important to enable you to practice nutritional therapy for cancer clients? Please list as many as you feel relevant in the open box below, you may wish to separate your answer into 'nutrition skills' and 'other skills' if you wish

☐ _____ (Open text box)

Q2 How did you acquire these skills and knowledge? Please indicate all that apply and add others if you wish.

- ☐ During my original NT professional training
- ☐ Through training in another healthcare discipline
 - Please add more detail here if you wish (open box)
- ☐ Additional post-qualification NT training (e.g. post-graduate study)
- ☐ Self-directed learning
- ☐ Specific CPD
- ☐ Other_____ (open text box)

Please tell us about any particularly helpful training courses/ resources/ programmes you have identified

useful training _____ (open text box)

Q3 Information needs and resources

What types of information do you need to support your work with cancer clients, and where do you generally look for this information? Please think of common queries you have, and list as many different information resources as you might use.

**I need information on ----- I generally refer to -----
(multiple lines)**

Q4 What are the most difficult questions to answer if any? – list as many as you wish

- ☐ _____ (Open text box) **(multiple lines)**

Q5 Please rate how useful you find these information resources to support you in formulating client advice, when looking for information and evidence on diets, nutritional supplements, client testing etc.

Indicate the score in the boxes on the left where 1 is least useful and 5 is most useful. Please rate all of them and add others if you wish. If you don't use any of these resources please use the 'Other' box to indicate where you have obtained information from

- ☐ CPD seminars or conferences
- ☐ Textbooks
- ☐ Professional Association newsletters
- ☐ Product information from suppliers
- ☐ Literature searches of peer-reviewed publications using e.g. PubMed/Medline
- ☐ Specific peer-reviewed journals
- ☐ CAM magazines such as 'CAM'
- ☐ Discussions with colleagues
- ☐ Web forums or blogs
- ☐ Other – please indicate (open text box)

Q6 If you were seeking information on treatments that your clients may be having, such as information on chemotherapy, radiotherapy and other mainstream cancer treatments and also interactions with food and supplements, how would you rate the usefulness of various sources? Indicate the score in the boxes on the left where 1 is least useful and 5 is most useful. Please rate all of them and add others if you wish

- ☐ Medicines information sources, such as British National Formulary or similar
- ☐ Clinical guidelines, such as NICE, NHS Evidence, or similar
- ☐ NT colleagues
- ☐ Other professional colleagues or contacts, such as pharmacists, nurses, doctors
- ☐ Other – please indicate (open text box)

Q7 What further information resources, if any, do you feel could be provided or improved to support the use of nutritional therapy for cancer clients?

☐ _____(Open text box)

Q8 Would like more work with cancer clients?

- ☐ YES (move to Q9, then 10)
- ☐ NO (move to Q10)

Q9 What barriers or problems do you feel are preventing you from doing more work with cancer clients?

☐ _____(Open text box)

Q10 How do you think these might be resolved?

☐ _____(Open text box)

Q11 Apart from information, what other resources, tools or arrangements, if any, do you feel would be beneficial for the practice of nutritional therapy with cancer clients?

☐ _____(Open text box).

Q12 How do consider most of your clients come to you?

- ☐ Self referral
- ☐ NHS referral
- ☐ Private medical referral

- ☐ Other CAM practitioner referral
- ☐ Other (open text box)

Q13 Any other comment you would like to make about working with cancer clients that is not covered by the previous questions

- ☐ _____(Open text box).

Thank you for participating in this research.

Appendix 4 - Questionnaire pilot feedback

Questions asked of reviewers:

- 1) Please make a note of any of the questions that were difficult to interpret, potentially ambiguous, or otherwise unclear
- 2) Did the order of questions seem logical?
- 3) Were there any areas that were not covered fully by the questions asked, that you thought should be included?
- 4) How long do you think it would take to complete the whole questionnaire, approximately?
- 5) Any other comments you have on the questionnaire design.

Reviewer 1 – experienced NT, very few cancer clients

I know it's not very helpful feedback when people have nothing to say, but ...the questionnaire seems clear and I didn't find anything confusing or ambiguous there. It poses some interesting questions, and I much look forward to seeing the outcome.

Reviewer 2 – experienced NT cancer practitioner and clinical teacher

Hi - questionnaire is good, easy to follow and the questions make sense and are easy to understand, but how about in question 1 adding a CAM centre for cancer patients?

Reviewer 3 – practitioner linked to a CAM cancer centre

Section 1

- Are you planning to involve a wide range of practicing NTs or only the ones that are CNHC registered? The reason I'm asking is because Q3 is only relevant for CNHC registered therapists. If you want to cover as wider audience as possible you may want to include an option for those who doesn't belong to CNHC. You may wish to include section on professional

bodies as I know that not all NTs belong to BANT either, unless the research specifically targets only BANT members.

- I think you may want to review Q10 in terms how it's presented as I had to re-read the second part of it twice to understand what's required but then, of course, it could be just me :)

Section 2

- I think Q1 could be improved by separating it into 2 areas - first being related to purely NT skills and second related to other skills (i.e. listening skills, counseling, etc)

- In Q2 the second box on training in another healthcare discipline may benefit from an open box as I think you may want know which discipline their acquired.

- I would also delete the word 'notably' as it may sound a bit ambiguous - how would you define 'notably useful' from just 'useful' ? (i'm probably being a bit picky though)

- I think Q8 is a bit ambiguous and difficult to answer. I would have replaced it with a couple of simple questions about general difficulties people experience in their work with cancer patients (see examples below):

What difficulties do you experience in your work with Cancer patients?

- open box

How could those problems/issues may be resolved in your opinion? -

open box

In addition to that you may ask if NT is happy to see more patients with cancer or even to work exclusively with cancer patients.

Reviewer 4 – experienced cancer NT

Part 1 in terms of establishing current status and activity - all good, flows well.

Part 2

Q5.. Include don't know or not using?

Is it appropriate to ask where patients come from, any nhs referrals?

Do NTs liaise with medics and if so at what level... GP, nurse, oncologist?

Are they using any functional tests eg genova ONE, stool, ASI?

Appendix 5 Cancer practitioner Interview guide

Working with people affected by cancer

Interviews and Focus Groups

The interviews and focus groups will be recorded and transcribed

Interview participants will be able to review their transcript if they wish, before it is analysed.

The questions are all open, I want to hear your story in these areas, there is no 'right or wrong' answer! You can decline to answer any of the questions if you wish.

- Tell me about your practice, the types of clients you see, etc
- Tell me about your experience in working with people affected by cancer, how long, etc
- What led you to working with people affected by cancer?
- Tell me about the rewards and challenges you have experienced in working with people affected by cancer
- How do you feel your training prepared you for this work, e.g. which skills were most important?
- How do you feel NT training might be developed or improved for this work?
- What barriers, if any, do you feel you encounter in working with people affected by cancer and how might they be overcome?
- What sort of resources and support do you feel NTs need for working with people affected by cancer
- Thinking about information you might use in your practice, what sort of information resources do you use and how do you access them? For example, if you had a client with a condition you hadn't encountered before, what sort of information would you look and where? How do you feel these resources might be improved?

- Thinking about working with people who may be seriously ill, how do you feel this might affect you?

Any other comment you would like to make about this area of nutritional therapy practice?

Thank you for taking part in this research.

Carol A Granger

Registered Nutritional Therapist

Professional Doctorate Student

Faculty of Science and Technology

University of Westminster

Cavendish Campus

W1W 6UW

London W1W 6UW

<http://www.westminster.ac.uk/research/graduate-school/current-students/doctoral-researchers/granger-carol>

Appendix 6 Non-cancer practitioner Interview guide

Working with people affected by cancer

Interviews with practitioners:

The interviews will be recorded and transcribed

Interview participants will be able to review their transcript if they wish, before it is analysed.

The questions are all open, I want to hear your story in these areas, there is no 'right or wrong' answer! You can decline to answer any of the questions if you wish.

- Tell me about your practice, the types of clients you see, etc
- What is your experience of working with people affected by cancer?

For those who may have had one or two cancer clients:

- What is your interest in developing this area of your practice?

For who are not particularly interested in working with cancer patients:

- Any thoughts about why you prefer not to work with cancer patients?

For who are interested in working with cancer patients:

- How do you feel your professional training prepared you for this work?
- How do you feel your skills and/or knowledge might be developed or improved to enable you to work with cancer clients?
- How do you envisage this training might be delivered, to be most effective for you?
- Thinking about working with people who may be seriously ill, how do you feel this might affect you?

- How do you feel might be helped to deal with these aspects of practice?
- What other resources and support do you feel NTs need for working with people affected by cancer?

Any other comment you would like to make about this area of nutritional therapy practice?

Thank you for taking part in this research.

Carol A Granger

Registered Nutritional Therapist

Professional Doctorate Student

Faculty of Science and Technology

University of Westminster

Cavendish Campus

W1W 6UW

London W1W 6UW

<http://www.westminster.ac.uk/research/graduate-school/current-students/doctoral-researchers/granger-carol>

Appendix 7 Professional Association practitioner committee group interview guide

Briefing sent before meeting to committee chair and read to team at start of meeting:

My hope in attending the meeting, is to understand from your team what they feel is the role that professional guidelines play in the NT profession, particularly for cancer practice. This is also be part of the research into cancer practice that is intended to support the profession in this clinical area.

What part do you feel guidelines play in professional practice?

How do you feel these relate specifically for professional practice?

How do you feel they should be developed?